



The Cystic Fibrosis Care Center at Arkansas Children's Hospital

Issue 5

Winter 2008

Building Bridges to Create Tomorrows

The Politics of Cystic Fibrosis

It seems that everywhere we go...the mall, grocery store, work...we can find someone discussing politics. Questions arise such as, "Who are you going to vote for?" or "What did you think of the debate?" The primary for Arkansas is just around the corner.

Some cannot wait to get out and take a stand, while others may not feel they have the time to ponder politics, feeling the pressures of everyday life. For many of us, these pressures go beyond the norm and include caring for or being a person with Cystic Fibrosis.

When we look at a person with CF we do not see a Democrat, Republican, or an Independent. We see an individual who needs an advocate. An advocate is one who pleads another's cause. Who is the CF person's advocate in the political arena? The answer is: The Congressional Cystic Fibrosis Caucus.

The Congressional Cystic Fibrosis Caucus was created to increase the awareness about CF on Capital Hill. The Caucus is led by Edward Markey (D-MA) and Cliff Stearns (R-FL). The Caucus provides the Cystic Fibrosis Foundation with a valuable tool to educate elected officials about the disease and spur action on issues beneficial to the CF community.

The Cystic Fibrosis Foundation stated that in 2007 the CFF and volunteers contacted 510

Congressional offices (95%) to discuss issues important to the CF community. The Congressional Cystic Fibrosis Caucus now has 116 members.

The CFF believes this election year is an important time to voice the concerns of those with Cystic Fibrosis and for your elected officials to prioritize CF issues.

In 2008 the Cystic Fibrosis Foundation and CF Advocacy Task Force will communicate with Congress about helping those with CF and bring us closer to a cure. There are three areas they will address:

1. Increasing government support of CF research.
2. Insuring access to health coverage for people with CF.
3. Raising awareness of Cystic Fibrosis.

Our Congressmen for Arkansas include:

1. **Marion Berry**
2. **Vic Snyder**
3. **John Bozman**
4. **Mike Ross**

As of January 25th of this year, not one of these Congressmen has joined the Congressional Cystic Fibrosis Caucus.

If you are interested in seeing the current Congressional Cystic Fibrosis Membership list, you can use this link:

<http://www.cff.org/GetInvolved/Advocate/CFcaucus/CaucusMembers/>

If you are interested in asking your Congressmen to join the Congressional Cystic Fibrosis Caucus, then go to the bottom of the list and click, "Ask your Member of Congress to join today."



A Note From Dr. Schelhase

Vital Health Questions

What are the questions and do you know the answers?

Do you know the important questions to ask regarding your child's health and how to either maintain or improve his/her health? Who should be asking these questions-the CF Foundation (CFF), your primary physician, your pulmonologist, the respiratory therapist, the nurse, your child, you? The obvious answer is that all of us should be asking these questions, but, most importantly, you (and the older child and adult with CF) should be. You are your child's best advocate. If you train your child well, then your child when he/she is older will become his/her best advocate. So. Beyond how is my child doing, there are at least four specific questions you should ask and know the answers to.

1. How are my child's lungs?

If your child is old enough to do pulmonary function testing or PFT's, then do you know his/her most recent FEV1 percent predicted (FEV1%)? FEV1 or Forced Expiratory Volume in one second is the amount of air blown out after a big breath during the first second of the test. Do you know your child's best FEV1% in the past twelve months? 80-100% is considered normal, but the closer to 100% the better. What is the goal? The goal of the CFF and our center is for your child to have a FEV1% of 98% when he/she graduates to the adult CF center. It is a lofty goal and will require hard work from you, your child and the CF team, but it is reachable for most CF children. Your CF team also wants to see either no change or less than 1% decrease in FEV1% over a one year time period. If your child's lung function is already less than 98% and can not be budged higher, then the goal should be to maintain the FEV1% at least where it is now. Having normal or near normal lung function as your child enters young adulthood means better quality of life and a longer life. If your child cannot yet do PFT's then the goal should be a normal chest examination and a normal or near normal chest x-ray. Has your child's CF doctor shown you your child's most recent chest x-ray?

2. How is my child's nutrition?

If your child is two years of age or younger, then

do you know his/her weight for length percentile (W/L%)? If your child is older than two years, then do you know his/her Body Mass Index percentile (BMI%)? Although these measurements are not the only way to measure nutrition, they are very important. Maintaining W/L% or BMI% at or a little above 50% is important. Children who have normal growth, especially during the first several years of life, have better lung function. Children whose W/L% or BMI% is less than 25% tend to have lower lung function. For your child to get to a W/L% or a BMI% of 50% or a little higher may be difficult to achieve, but it is possible for most children with CF. It may require hard work for you, your child and the CF team, but the results are worthwhile. Having good nutrition and lung function as your child enters young adulthood means a better quality of life and a longer life.



3. What germ or bacteria is growing on my child's respiratory culture?

Many children with CF and many normal children grow *Staphylococcus aureus* (or *S. aureus*) and different types or species of Haemophilus on their respiratory cultures. Methicillin-resistant *S. aureus* (MRSA) is becoming more common and is resistant to some of the more common antibiotics. These bacteria are important, but in most circumstances antibiotic treatment is only needed when the child with CF is sick. The bacteria that are more concerning to the CF team and thus should be more concerning to you are *Pseudomonas aeruginosa* (*P. aeruginosa*) or other Pseudomonas species, *Burkholderia cepacia* (*B. cepacia*) or other Burkholderia species and *Stenotrophomonas maltophilia* (*S. maltophilia*). One of the reasons we do respiratory cultures at each clinic visit is to find out if one of these bacteria have infected or is chronically infecting your child's lungs. If the culture is positive for the first time, then this represents a new infection. If the culture becomes negative and then becomes positive later, then this represents a recurrent infection. Almost all CF doctors will prescribe a one month or longer antibiotic therapy to eradicate (treat and potentially get rid of) these new and recurrent infections. If the culture is repeatedly positive, then this represents a chronic infection. Chronic infections can be controlled but are not usually eradicated. What are the treatments?

continued on page 3.



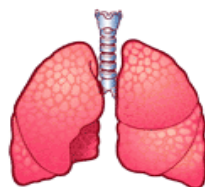
Chest physiotherapy (CPT) or airway clearance 2-4 times per day and Pulmozyme daily are used to help your child cough up the thick mucus found in CF airways. Most CF doctors believe that all children should be started on CPT early in life. Pulmozyme should be started by six years of age and can be started sooner. CF patients who have grown *Pseudomonas* within the past year should be on every other month inhaled TOBI and three times per week Zithromax (Azithromycin). When used appropriately all of these therapies have been shown to improve and/or slow the decline in lung function. Remember the goal for FEV1% is 98%. If your child has grown *Pseudomonas*, then he/she should be on these therapies. If your child has repeatedly grown *S. maltophilia* or *B. cepacia*, then talk to your CF doctor about what can

be done to slow these infections.

4. What new therapies are available?

Being an advocate for your child means following what is happening in the CF world, asking your CF doctor what is new, reading about CF in the news or online, visiting the CFF website (www.cff.org) often and participating in clinical research. New therapies do not become available without CF patients participating in clinical research trials. Being informed, asking questions, learning about CF, being open to participating in a clinical research trial, asking whether or not your child is on all the therapies that he/she should be on are your responsibilities. They are not just the responsibilities of your CF team. You are on that team! Know the questions and the answers for your child! It is vital to their health, quality of life and length of life.

Corner For Kids!



Valentine's Day is right around the corner!

This is a time to make and send Valentine's cards, roses and candy. What better time of the year to remind yourself to LOVE YOUR LUNGS!!!!

Your lungs are amazing! They allow you to breathe, talk to your friend, shout at a game, sing, laugh, cry, and more! And speaking of a game, your lungs even work with your brain to help you inhale and exhale a larger amount of air at a more rapid rate when you're running a mile—all without you even thinking about it once! You can show **love for your lungs by exercising and even playing games!**

Breathing Games for your Lungs!!!

- 1. Bubbling Water: Place a straw in a glass that is filled halfway with water. Then, blow gently through the straw and make bubbles in the water!**
- 2. Cotton Wool Balls: Place a cotton wool ball in the palm of your hand and blow gently to make the ball fly off your hand. Alternate with someone else to see who can make the ball go farthest.**



Meet a Member of the Team!

Name: Angel Weiss

Job: Respiratory Therapist

- **How long have you been working with CF children?** About 2 years
- **What do you like best about your job?** There are lots of great things about my job. I love getting to know the kids and their families. I feel like I have made tons of friends that I care about greatly. Believe it or not, I even MISS some of my patients when they leave, although I am always happy when they are well and at home where they should be. ACH is a great place to have when you need it, but there's no place like home!
- **Please share with us something funny or surprising that has happened to you while working at ACH.** First of all, my job has just confirmed something I've suspected for years. **KIDS ARE HILARIOUS!** I am always cracking up over something someone has said. But the most surprising thing is the impact we have on kids lives. I've had kids come back after not being in the hospital for 6 months and smile and yell, "Angel!!!" That's cool. I think that most of them think I'm a kid, too! I've found that we can get so much done, (vest, CPT, updrafts, MDI, or whatever) if we just have a little fun!
- **If you had to choose just one important thing to say to all CF kids, what would it be?** Take extra special care of yourself, because YOU ARE WORTH IT!
- **Please give a brief description/definition of what you do in your job.** A respiratory therapist does different things. With most CF patients, we administer medicines to improve breathing. We perform airway clearance, either manually (CPT with little babies) or with vests (for our bigger kids and young adults). There are therapists that do PFT's (pulmonary function tests) regularly to monitor any changes in the lungs. We draw blood (OUCH!) to check oxygen levels. In the critical care areas, we take care of the ventilators. Sometimes I just tell people I'm a professional snot sucker! Gross as it may sound, if it will help, respiratory therapists do it!



Cystic Fibrosis Foundation: Arkansas Chapter News

Mark Your Calendars!!!

Wine Opener-Little Rock: April 17, 2008

GREAT STRIDES-Hot Springs: Sept. 6, 2008

Wine Opener-Northwest Arkansas: April 25, 2008

Swing for a Cure Golf Classic-Little Rock: Sept. 2008

GREAT STRIDES-Fort Smith: May 10, 2008

Breath of Life Gala-Little Rock: Nov. 2008

GREAT STRIDES-Jonesboro: May 17, 2008

GREAT STRIDES-Little Rock: May 17, 2008

Ozark Charity Golf Classic-Rogers: June 2008

Catch a Cure Bass Tournament-Central Arkansas: Sept. 2008

GREAT STRIDES-Bentonville: Sept. 6, 2008

"In our quest to find new treatments and a cure for CF, there is no such thing as doing enough or doing it fast enough."

ROBERT J. BEALL, PH.D.
PRESIDENT AND CEO,
CYSTIC FIBROSIS FOUNDATION



In the Spotlight!



Name: Samantha Tackett

City & State: Schlater, MS

Age: 16 **Grade:** 11th

Favorite School Subject: Bible, Algebra 1 & 2, Keyboarding

Siblings / Pets: I have one brother who is 13. I also have two cats and one dog.

What do you like to do in your spare time? I play violin and hang out with my friends and family.

Do you have any hints that you could give to other CF kids about their treatments, meds, etc? Do your treatments everyday because the more you skip the more you get sick!

If you could have one wish, what would it be? To be on a deserted island with Zac Efron or Orlando Bloom!!!

Awards and Accomplishments: I would have to say my greatest accomplishment would be learning to play the violin.

What are your future plans? My future plans are to go to college and become an accountant.

Fun Food Finds

Beth's Mexican Dinner Casserole



Ingredients:

- 1 can kidney beans, rinsed and drained (15.5 oz)
- 2 cloves garlic, minced
- 1 onion, chopped
- 1 4 ounce can diced green chili peppers
- 1 lb ground beef, crumbled
- 12 -(6 inch) flour tortillas
- 1- 19 ounce can enchilada sauce
- 2 cups Spanish rice, prepared
- 8 ounces shredded Cheddar cheese

Preparation:

1. Preheat oven to 350 degrees (175 degrees C). Lightly oil a 9X13 inch baking dish.
2. Brown the ground beef, garlic, onion and chili pepper. Drain. Add enchilada sauce and kidney beans to mixture and heat through.
3. Place a small layer of the meat mixture on the bottom of the prepared baking dish. Be sure to cover the bottom of the dish as completely as possible. Place a layer of tortillas next. Then spread the top with refried beans. Sprinkle cheese on top.

Put a layer of meat mixture next. Place another layer of tortillas and spread with Spanish rice. Sprinkle with cheese on top. Place the remainder of the meat mixture on top and sprinkle with cheese.

4. Cover, and bake for 30-45 minutes. Uncover, and continue baking for an additional 15 minutes, or until the casserole is bubbling and the cheese is melted.

Serve with a salad!

Nutrition Facts:

Servings: 8

Calories per serving: 605

Calories from fat: 242.77

Cholesterol: 77.33 mg

Flu Shot Reminder!!!

The Arkansas Cystic Fibrosis Center would like to remind patients and families of the importance of getting a yearly flu shot. The flu can worsen pulmonary disease in CF leading to a decline in lung function or respiratory infection. This can result in a long illness requiring antibiotics or hospitalization. Family members living in the same house should also receive a flu shot to reduce the risk of spreading flu to the person with CF.

Please call the pulmonary office at (501) 364-1006 for questions regarding the flu shot.

Last year, 95% of our patients reported receiving the flu shot. Let's continue the great job and shoot for a new record this year!



How to Reach the CF Team:

Pulmonary Office:	(501) 364-1006	Physicians, Specialty Nurses, Respiratory
Main Hospital:	(501) 364-1100	After-Hours Pulmonary Physician On-Call
Chaplain:	(501) 364-1824	Kenneth Myers
Child Life:	(501) 364-1412	Amelia Harris
Clinical Nutritionist:	(501) 364-7533	Heather Harden
Education/Teacher:	(501) 364-1412	Kathy Robinson
Psychology :	(501) 364-1021	Dr. Anne Stermock
Social Work:	(501) 364-6537	Mary Jo Chambers

Check out these great Websites!

[http://
cf.starlightprograms.
org/](http://cf.starlightprograms.org/)

[http://
arkansas.cff.org](http://arkansas.cff.org)

<http://www.cff.org/>

We'd love to hear from you!

The Family Advisory Board would love to hear from you concerning this newsletter & other Cystic Fibrosis issues that are of concern to our fellow parents and patients.

Please send us an email @ cfnewslettercommittee@yahoo.com if:

- You have a newsletter story idea.
- You would like your child/yourself to be featured in our Spotlight section .
- You have questions or comments that you would like the Family Advisory Board to address.

We look forward to hearing from you!

Our Mission . . .

We, the Cystic Fibrosis Center Family Advisory Board at Arkansas Children's Hospital, serve to build a bridge between the healthcare team, families and patients with Cystic Fibrosis.

Our Vision . . .

Through communication, education, and self-reflection, we will provide personal insight to the CF team as well as to those dealing with the disease in their daily lives. Ultimately, it is our vision to further enable patients with Cystic Fibrosis to continue to "live well and prosper."

Please be aware that this information is provided to supplement the care provided by your physician. It is neither intended or implied to be a substitute for professional medical advice. Always seek the advice of your physician or other qualified health provider prior to starting any new treatment or with any questions you may have regarding a medical condition.

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