



The Cystic Fibrosis Care Center at Arkansas Children's Hospital

Issue 1

Summer 2006

Building Bridges to Create Tomorrows

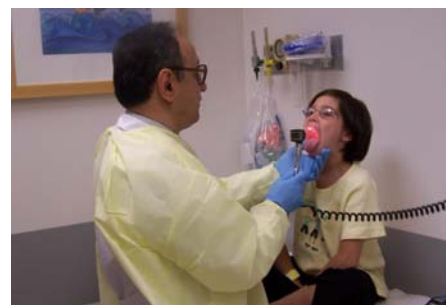
Do I really NEED to go to clinic?

Have you ever asked yourself, "Do I really need to go to clinic? I feel fine." Or maybe you've missed a few treatments here and there and you would prefer not to get "the lecture." Perhaps even more complex is the issue of financial concerns. A CF parent may have problems taking a day off without pay or even face the difficulty of affording the trip to clinic.

Whatever the case, there are very real reasons that CF patients and parents alike don't maintain quarterly visits as is currently recommended by the Cystic Fibrosis Foundation. As a matter of fact, according to foundation statistics, only about one-third of CF patients at ACH attended the minimum of four visits in 2005.

You might ask, "What is so important about coming to clinic on a regular basis?" Studies have consistently shown a direct correlation between clinic visit compliance and median age of survival in CF patients.

Plainly spoken, those who come to clinic regularly live longer, healthier lives. Of all the variables in CF that can't be controlled, here's finally one that patients and families can make happen!



Let's work together to make CF clinic visits a top priority. Are there ways that the Cystic Fibrosis Care Center at ACH can help you? Do you have trouble scheduling an appointment? Do you have transportation issues? Are there other obstacles or concerns that keep you from visits? Please send your thoughts to cfnewslettercommittee@yahoo.com and watch for further updates in upcoming issues.

CF Center Creates Family Advisory Board

As Center director Dr. Dennis Schellhase puts it, "We're on the cutting edge" with the creation of the first CF Family Advisory Board. Made up of parents and caregivers of ACH CF patients, the twelve voting member board is involved in just about every aspect of the Center's care including patient and family education, transition to adult care, inpatient and outpatient visits, and more.

The board was created so that families could take a more active role in the Center and to provide insight into ways to further improve quality of care. FAB members were chosen by application and elected for a term of one to two years. Duties include attending quarterly meetings and performing various sub-committee tasks. If you have suggestions or concerns that you would like the CF Family Advisory Board to address, please send an email to cfnewslettercommittee@yahoo.com.





A Note From Dr. Schellhase

Your Center has embarked upon an ambitious program of revamping everything we do with the goal of improving health outcomes. Our outcomes are not bad, but we have room to improve. Improving your child's lung function and nutritional status will require a partnership between you and your Center's healthcare team. You should expect us to know current "best" practices to keep your child as healthy as possible, to answer your questions, to work together with you in developing the best possible treatment plans and to provide services in an efficient, timely manner. We expect you and your child to

learn all you can about CF, to be optimistic and set goals for living well, to come to CF clinic at least every three months, to ask questions, to work with us to come up with the best possible treatment plans and to follow through on those treatments to the best of your ability. Together we can work toward the goal that your child with CF will live as normal, as good and as long a life as possible.



In the Spotlight- Mackenzie Jobe



"I can't wait to be sixteen so that I can get a Jeep and drive."

Nine year-old Mackenzie Jobe may have CF, but that doesn't seem to slow her down. In addition to the rigor of daily CF treatments and maintaining straight A's, she manages to find plenty of time to play soccer and perfect her technique in gymnastics. Mackenzie also enjoys spending time hanging out with her friends. We recently caught up with her to ask her a few questions and here's what she had to say:

Q: Tell us about your siblings & pets.

A: I have one younger sister, Peyton. She loves penguins and likes to cook. I also have two dogs, Kate, a Heinz 57 dog (a mutt) and Eddie, a Jack Russell Terrier.

Q: Do you have any hints that you could give other CF kids about their treatments?

A: Play games when you're doing your treatment to make treatment time fun. I like to play Sorry, Monopoly Junior, Blink, and Sleeping Queens.

Q: If you could have one wish, what would it be?

A: That the doctors find a cure for CF!

Q: Tell us about school.

A: I'm in the 4th grade. My favorite subject is Math, and I was spelling bee champion in 3rd grade.

Q: What are your future plans?

A: To go to the University of Arkansas at Fayetteville and become a teacher. I want to go to Disneyland and the beach, and I can't wait to be sixteen so that I can get a Jeep and drive.



Corner For Kids!

A	C	O	U	G	H	I	N	G	A	C	R	P	E	P	T	D	E
N	Y	M	L	S	A	N	O	H	U	O	E	A	S	U	R	P	H
P	S	G	P	T	R	P	S	E	M	S	G	N	U	L	C	N	O
A	T	W	E	I	G	H	T	I	W	A	H	C	Y	M	E	O	S
Z	I	P	W	A	R	O	B	G	Z	I	F	R	I	O	F	I	P
V	C	H	E	C	K	U	P	H	P	R	O	E	B	Z	W	T	I
S	F	K	I	L	S	A	L	T	B	E	M	A	G	Y	R	C	T
L	I	T	S	O	I	Z	N	R	S	T	H	S	N	M	U	E	A
T	B	C	E	A	N	A	E	T	N	C	P	I	D	E	C	F	L
S	R	N	I	H	U	C	B	G	I	A	I	R	W	A	Y	N	Y
E	O	A	R	N	S	R	U	H	F	B	M	E	H	N	G	I	P
M	S	G	O	A	E	D	L	P	A	V	I	T	A	M	I	N	S
Y	I	T	L	Z	S	L	I	B	U	Z	E	O	K	B	O	C	U
Z	S	I	A	W	Y	N	Z	S	N	T	F	C	T	A	Z	E	C
N	N	S	C	O	L	D	E	U	F	S	B	P	Y	I	H	K	U
E	B	H	I	M	N	I	R	E	V	I	L	V	Z	U	C	A	M
P	U	C	T	R	E	A	T	M	E	N	T	S	G	C	T	S	E

CF Word-Find

Look down, across, or diagonal to find these words:

- | | |
|-----------------|------------|
| Airway | Liver |
| Antibiotics | Lungs |
| Bacteria | Mucus |
| Calories | Nebulizer |
| Checkup | Pancreas |
| Cold | Pulmozyme |
| Coughing | Saline |
| Cystic Fibrosis | Salt |
| Enzymes | Sinuses |
| Height | Treatments |

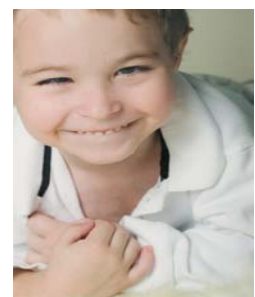
See if you can find them all before the end of your treatment!

You know you're a kid with Cystic Fibrosis when . . .

1. Even your cat knows where your enzymes are.
2. Your family members keep tripping over your nebulizer hose.
3. Your food comes in a pick-up truck!



Do you have a funny one-liner to complete the above statement? Send your responses to cfnewslettercommittee@yahoo.com. You might see it published in the next newsletter!



Cameron Wilkins
Age 3



Elisabeth McClintock
Age 8



Carter Wilkins
Age 6 months



Meet a Member of the Team!

Name: Lauren Willis, RRT-NPS

Job: Pulmonary Patient Care Coordinator

Special Focus: Respiratory Therapist on CF Team

- **How long have you been working with CF children?** I started working at ACH in 1996. I initially worked with patients with CF giving treatments in the hospital as a new graduate for 6 months before taking a position in the CVICU where I worked for 2 ½ years. In 1999, I took my current position working with the pulmonary group and resumed involvement with CF team and have been here since!
- **What do you like best about your job?** My favorite thing is working with children and young adults. They have such great attitudes, are so resilient, and have a fabulous sense of humor. I have some creative freedom in my job which makes it fun - including organizing CF day and other conferences, the CF website, drafting educational material, and serving in an educational role to spread an awareness of CF.
- **Please share with us something funny or surprising that has happened to you while working at ACH.** For the romantics in the group, I met my husband at ACH. He's a Respiratory Therapist, too. A funny patient story is the little boy with CF who decided his breathing treatments took too long - so he just drank the medicine. It is only funny because he wasn't hurt. PLEASE DON'T TRY THAT AT HOME. Breathing medicines must be BREATHED into the lungs to work. Ha!
- **If you had to choose just one important thing to say to all CF kids, what would it be?** No eye-rolling, please - Prepare for the future: Keep up those respiratory treatments, do well in school so you can get a good job, and mind your parents.



Achhho!!!



As the fall season approaches, the Arkansas Children's Hospital (ACH) Cystic Fibrosis (CF) Center would like to remind patients and families of the importance of receiving a flu vaccine. Influenza (flu) can worsen lung disease in CF leading to a decline in lung function or a respiratory infection requiring antibiotics or a hospitalization. The ACH CF Center is tracking the number of patients who receive a flu shot as part of an ongoing Quality Improvement project. Last year 94% of patients with CF received a flu shot. **Let's make this year 100%!** Watch your mail for additional information about when and where flu shots will be available.

CF Family Day 2006

On Saturday, September 23rd, family members of ACH Cystic Fibrosis patients can join together in the fifth annual CF Family Day. The event is a great opportunity to catch up on the latest advances in treatments and research, as well as to share experiences with other CF families. In addition to workshops and presentations led by ACH & UAMS faculty members, attendees will have the opportunity to visit with vendors who carry and specialize in many of the products that CF patients use daily.

Guest speaker Kristin McFall will be highlighted at this year's CF Family Day as she speaks of living daily with the disease for 27 years. She is an Education Resource Specialist at for Hill-Rom and has the unique ability to temper living with cystic fibrosis with humor and honesty.

Look for brochures detailing CF Family Day 2006 in your mailbox and at CF Clinic. Mark your calendar!



Introducing... E-Pals!

The newsletter committee understands how difficult it is for Cystic Fibrosis patients to have contact with one another due to infection control guidelines. We would like to help match CFer's together who might enjoy corresponding via email or regular mail. If you are interested in the email option, please fill out the form and send your responses to cfnews-lettercommittee@yahoo.com. If you are interested in the "snail mail" option, please send your answers to the questions below and your request to: Vickie Marshall-1112 W. Pecan Street-Rogers, AR 72756. Your information will be kept confidential and only shared with a potential e-pal match after signing a release form that will be sent to you via US mail.

Name: _____

Email/Mailing Address: _____

Age: _____ Grade: _____

Circle gender: male female

Interests/Hobbies: _____

Would you like to be matched with a boy or girl? _____

Parent Name(s): _____

Release form address: _____

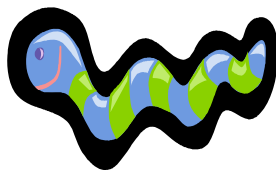
Fabulous Food Finds!

Dirt Pudding

Prep time: 15 minutes

Ingredients:

- 1 c. whole milk
- 1 c. heavy cream
- 4.5 oz. pkg. vanilla instant pudding
- 3/4 c. dry milk powder
- 8 Oreo cookies, crushed
- 4 gummy worms



Stir together milk and heavy cream. With wire whisk, beat pudding mix and dry milk powder into milk and cream mixture for 2 minutes. Stir in crushed Oreo cookies. Immediately pour pudding into 6-oz. clear cups. Put pudding into the refrigerator. Pudding will be soft-set and ready to eat within 5 minutes. Serve with a gummy worm on top.

Serves: 4 (1/2 cup servings)

Nutritional analysis per serving:

- 549 calories 282 mg calcium
- 10 g protein 650 mg sodium
- 31 g fat

Ants on a Log

Prep time: 5 minutes

Ingredients:

- 2 celery sticks
- 6 tbsp. peanut butter
- 2 tbsp. raisins



Wash the celery and cut it into pieces. Each piece should be about 5 inches long. Spread peanut butter in u-shaped part of celery from one end to the other. Press raisins gently into peanut butter.

Enjoy your ants on a log!

Serves: 2 (1 celery stick per serving)

Nutritional analysis per serving:

- 317 calories
- 12 g protein
- 24 g fat
- 266 mg sodium



How to Reach the CF Team

CF Websites

www.cff.org

www.cystic-l.org

www.cforward.net

Let us know if you have favorite CF sites that you'd like to share.

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) 364-1306	Dallas Carnahan
Education/Teacher:	(501) 364-1412	Kathy Robinson
Psychology :	(501) 364-1021	Dr. Anne Stermock
Social Work:	(501) 364-6537	Mary Jo Chambers

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 or patient pictures.
- 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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