



The Cystic Fibrosis Care Center at Arkansas Children's Hospital

Issue 7

Summer 2008

Building Bridges to Create Tomorrows

ACH Has a "Nose" for News!!!



The Arkansas Children's Hospital Cystic Fibrosis Care Center is pleased to announce the 7th Annual CF Family Resource Day. Registration begins at 8:30 a.m. on Saturday, 27th at the ACH Brandon Conference Center- South Campus.

The Family Day will run until 3 p.m. The event is open to family members, friends, and caregivers of CF patients. Due to the risk of cross-contamination of bacteria, patients will not be able to attend.

Listen to what others who have attended the event in years past have had to say:

1. I just love going to Family Day each year. It's nice to see others who are facing the same things that I am and I feel like I'm recharging my batteries each year.
2. If ever I doubted the team approach to my boys' care, I certainly know they are a team after I attend one of these events. The staff is all smiles and it shows that they worked together for a long while to put together this day for us.
3. One of my favorite parts of the day is visiting with all the vendors and getting the freebies. The pens, notepads, dishwasher baskets, and prizes are GREAT! It's also a perfect time for me to talk to the vendors that we use and tie up loose ends.
4. I like the lunch workshops. We get together with other parents and learn so many things about how they manage their child's day-to-day care.
5. I wouldn't miss it (Family Day) for anything! I just wish that more parents would come out and join us. Once they've been, they would never miss it again!

In addition to the event being free of charge, \$20.00 gas cards will be given to the first 20 families (one per family) to sign in on the day of the event AND who have traveled farther than 50 miles. For more information or to RSVP to the event, contact Lynda Latourelle in the pulmonary office or email: pedspulmonary@uams.edu

Also, don't forget to bring a picture of your CF child(ren) to show off. The Family Advisory Board will laminate pictures for the family members to wear throughout the day on lanyards. Photos should be 4x6 or smaller. We hope to see you there!



Greetings from 4B and 4C Medicine

As you can see from our greeting, our units have had a name change recently. The whole of ACH is undergoing a new "Way Finding" initiative which will make it easier for parents and families to negotiate our ever changing campus. Over the next few months all room numbers will also change so that each unit has sequential numbers rather than the confusing numbers we currently have.

As ACH's number one service standard is SAFETY, 4B and 4C are undergoing some construction work to ensure the safety of our patients. Currently our units do not have sprinklers in the patients rooms as this was not required when the current patient tower was created. Since that time, the requirements for hospital construction have changed and the value of the individual sprinklers in ALL patients rooms has been realized. 4B and 4C are two of only 4 units in the entire hospital without sprinklers so it was decided that this upgrade must occur as soon as possible. 4C is currently closed for this remodel for approximately 4 weeks. When 4C is completed, then the same upgrade will occur on 4B. All construction should be completed by the end of October. When each of our units is closed, CF patients will be given priority for beds on the unit which is currently open. All the nurses from the units are combined so you will still see the familiar faces of your care staff.

Are you tired of being in your rooms all day when you are in the hospital? If that is a "yes," here are a couple of things that are available for you:

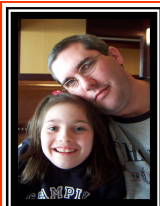
1. Ask your doctor for a "Pass." This is a short period that can give you some time away from the hospital. This has to be granted by your MD and happen around your scheduled treatment times. The Pass time must be AWAY from the ACH campus so we can insure we are being compliant with our infection control policy.
2. Physical therapy time can be done on the roof, weather and staff permitting.

In order to give more options to you for increasing your physical activity, the units now have available a portable treadmill which can be used in your room during your PT time. We also have a Wii that PT can use for activities such as tennis, bowling and dancing. Both of these options will be offered to you during your stay by your physical therapist.

As always, if you have questions or suggestions for improving your stay on our units, please don't hesitate to contact Penny Ward, Director at wardp@archildrens.org We can only be great if we do this together.



Dads, CF, and School



**Brian
&
Emma**



What age and grade level is your child?

Emma is ten years old and in the fifth grade.

What type of school does your CF child attend?

She goes to a public school.

Did you work with your school on developing a 504 plan or IEP for your CF child and if so, how did that process work?

Emma has had a 504 plan since kindergarten. Our school is very accommodating, but we do have to initiate quite a few things each year to get things going.

As a CF parent, what changes do you make in your child's routine, treatments, etc during the school year?

Things get pretty crazy during the school year, so Julie (my wife) and I have a pretty specific routine that we follow. We're more relaxed during the summer, but we have medicines organized in a daily pill organizer during the school year with a med list taped to the inside of the cabinet to double-check ourselves on those sleepy mornings. We also talk with Emma's teachers each year to clear her doing homework during her evening vest treatment. Her handwriting can be pretty interesting, but it sure makes it easier to do all at once.

How does your child deal with medications in the school setting?

Emma manages her own enzymes. She always takes her lunch to school and she keeps them in her lunchbox. Her teacher kept up with them in the earlier grades, but we transitioned to her managing her own meds last year, as she got them out of a lock box in her classroom and logged her own intake. The added responsibility allowed us to track her numbers while she maintained the sole responsibility of managing her own enzymes.

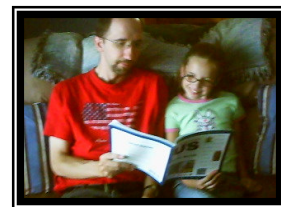
What is the hardest part for your CF child when balancing school and CF?

It sometimes seems that there just aren't enough hours in the day! There's a very fine line between creating an atmosphere where the chronically ill child feels different or isolated and pushing too hard to make things "normal."

How do you deal with your child's treatment regimen when school friends are over?

We have always tried to be up-front and explain the process so that it makes both Emma and her friends comfortable. Her buddies have been known to hook up to her vest and pretend to be aliens at times. We also have a little five year old neighbor who eats her Sweet-Tarts before meals and says, "I have to take my "zymes" before I eat."

**Timothy
&
Elisabeth**



What age and grade level is your child?

Elisabeth is ten years old and in the fifth grade.

What type of school does your CF child attend?

Elisabeth attends the Arkansas Virtual Academy. This is a "public" school that covers all of Arkansas. The difference between this school and the traditional public school is that my wife, Deborah, teaches her at home using the K12 curriculum, used by the Academy. Elisabeth has a teacher that she has conferences with and sends periodic work samples to.

Did you work with your school on developing a 504 plan or IEP for your CF child and if so, how did that process work?

Yes, each year my wife has a conference call and participates in an Illuminate session online with Elisabeth's ARVA teacher and another faculty member. They develop and type up the plan right in the Illuminate screen-online- during the conference. Each year my wife talks with Elisabeth's new teacher and "educates" her about CF in general. You may wonder why Elisabeth even needs a 504 plan if she does her schoolwork at home. She needs one to cover the state testing situations that occur each year, and also for school records so if she had a period of say... hospitalization-then the school can explain to their superiors that Elisabeth has CF and that the school has contingency plans set up for her.

As a CF parent, what changes do you make in your child's routine, treatments, etc during the school year?

Actually, we do not have to make too many changes. We start going over her schoolwork in the mornings while she is still on her treatment- she is a "captive" audience.-haha!

How does your child deal with medications in the school setting?

Since Elisabeth does her school at home this is not an issue. But in other situations such as church or eating out, places we know there will be food-she carries enzymes in her purse to use.

What is the hardest part for your CF child when balancing school and CF?

In Elisabeth's particular schooling situation (being at home) things pretty much stay on the same course with her CF care.

How do you deal with your child's treatment regimen when school friends are over?

Elisabeth has always been very open about her CF. When friends come over, or she is at their house she continues to do the same schedule she would normally. Kids are inquisitive and welcome explanations about why she had to use the vest or take certain medicines. Honesty is the best policy.



Care-Free Talk...Mom to Mom!



We CF moms do some pretty strange things at times, many of which we won't admit to the general public. So that you don't feel all alone, I'll name a few possibilities to see if they ring a bell: Have you ever gotten so tired of describing sputum that you've actually taken a picture for the doctor's viewing pleasure? What about licking your child's forehead to see if, just by chance, the salty taste had disappeared? (OK, so maybe you've just kissed him and nonchalantly licked your lips afterward. Some of us are more discreet than others.) And finally, have you longed of owning one of those little reminder recording devices so that you could save the word "breathe" to play repeatedly during treatments? If you answered yes to one or more of the above, you might be a CF mom. Perhaps one of my favorite CF mom hobbies is one that I haven't shared with many. I just **LOVE** to read word-for-word those tiny pamphlets that come in the medicine boxes. Well, I should qualify. They look tiny, but when opened, they're written in microscopic font and contain at least a million or so words. And talk about over my head...

As the story goes, one boring afternoon I decided that I needed some reading material, so I grabbed the pamphlet out of the Pulmozyme box. I opened its many folds and noticed in bold print the following message: **"WARNING-DO NOT TAKE THIS MEDICATION IF YOU HAVE AN ALLERGY TO CHINESE HAMSTER OVARY PRODUCTS."** Now I've read lots of things that have boggled my mind, but what kind of person knows that he's allergic to Chinese hamster ovaries? I'll guarantee you if I knew, I certainly wouldn't admit it! Just underneath the warning, I read:

"Pulmozyme...is a sterile, clear, colorless, highly purified solution of recombinant human deoxyribonuclease I,...,an enzyme which selectively cleaves DNA. The protein is produced by genetically engineered Chinese Hamster Ovary (CHO) cells containing DNA encoding for the native human protein."

Can you imagine my thoughts after reading that? You got it! It was all crystal-clear and I knew everything I needed to know about Pulmozyme. And in case it was a little hazy for you, here's my CF Mom version:

" Human enzymes were used in the making of Pulmozyme, but it was cheaper to manufacture these little Chinese hamsters to produce the protein. Or better yet, maybe they just create the hamster ovaries without the creature and "cut out the middle-woman"-so to speak. However, we shouldn't be alarmed because the protein has been encoded to mimic human protein and not that of the Chinese hamster. Therefore our children will not be prone to gnawing on wood chips or spinning around in circles, gaining pleasure out of getting absolutely nowhere."

OK. So maybe I didn't understand **EVERYTHING** I read, but interpreting the excerpt certainly added entertainment value to the day! I did come out with some benefit from my research, though. I asked myself, "Is it really necessary for me to know exactly what role the Chinese hamster plays in the making of Pulmozyme to effectively pour the medication into the nebulizer cup?" I think not. I would like to know, though, what kind of fellow sits around and thinks, "Eureka! Maybe we should try using Chinese hamster ovaries to treat CF patients!" I just can't imagine the origin of such thoughts. I now understand that I should look at pamphlet reading as a mere hobby and leave the technical stuff to the experts. Heck, I didn't even know hamsters had nationalities!

Care-Free Mom

Corner For Kids!

KIDS MAD LIBS

Fill in the following and then insert the words into the story. Don't look at the story first!!!! (page 5)

- | | | |
|-----------------------------------|---|-----------------------|
| 1. A mode of transportation _____ | 2. The name of someone in your family _____ | 3. An animal _____ |
| 4. A color _____ | 5. A number _____ | 6. A place _____ |
| 7. The name of a friend _____ | 8. A verb ending in "ing" _____ | 9. A number _____ |
| 10. An adjective _____ | 11. A verb _____ | 12. A body part _____ |
| 13. A verb ending in "ed" _____ | 14. A thing _____ | 15. An animal _____ |
| 16. A feeling _____ | 17. An adjective _____ | |



Meet a Member of the Team!

Name: Heather C. Harden, MS, RD, LD

Job: Clinical Dietitian for the CF Team

- **How long have you been working with CF children?** I've been working here at ACH since September 2006 and have worked with the CF Team since that time.
- **Please give a brief description/definition of what you do in your job.** I assess the CF patients' nutritional status and calculate how many calories that they need per day. Then, I talk with the patients and their families about strategies for meeting their calorie and weight goals.
- **If you had to choose just one important thing to say to all CF kids, what would it be?** Remember that you are all so special, with unique gifts to offer the world. Also, take time to enjoy each day because as the quotation says, "Life is not measured by the breaths we take, but by the moments that take our breath."
- **What do you like best about your job?** I really love the fact that I get to develop relationships with the patients and their families, and it feels good when I'm able to help make someone healthier.



Cystic Fibrosis Foundation: Arkansas Chapter News



The Arkansas Chapter of the Cystic Fibrosis Foundation (CFF) will honor Larry Choate, chairman and CEO of Arvest Bank Little Rock, and a supporter of the CFF, with the 2008 Breath of Life Award at its first annual Breath of Life Gala, on Saturday, September 27, at the Doubletree Guests Suites. This gala has significant importance, as it is the first Breath of Life Gala being held in Arkansas. The black-tie event features an evening of surprises, all lead by master of ceremonies, Today's THV meteorologist, Tom Brannon. The night will begin with a cocktail reception and exclusive silent auction at 7 p.m., followed by dinner, a live auction, and the CF Foundation's annual awards presentation. The auction will feature many outstanding items, including an elite trip for the Kentucky Derby and a golden retriever puppy. Live entertainment will be provided by Bob Boyd Sounds. The Breath of Life Gala will offer an elegant evening for all CF families, sponsors, and community to celebrate life, celebrate research milestones, and commemorate the launch of the Arkansas Newborn Screening program. The event will be held on the same day as the Arkansas Children's Hospital CF Family Day. Our hope is that CF family members will attend both events.

The CF Foundation will be giving awards in the following categories: Breath of Life Recipient, Hope Award for Advancement in Research or Care, Milestone Award, Great Strides Corporate Team Award, Great Strides Family Team Award, Great Strides Chair Award and the Claudia Fulton Volunteer of the Year Award. A block of rooms has been reserved for Friday, September 26th and Saturday, September 27th at the Doubletree Guest Suites for a special rate of \$119.00/night. Please reserve by September 5th by calling 501-372-4371; ask for "Cystic Fibrosis" when reserving your room. For more information or to reserve your ticket, please contact Jennifer Maune at 501-371-0233.

The CF Foundation is also holding the Northwest Arkansas GREAT STRIDES walk on September 6th at the Bentonville Plaza. The 11th annual event is a family oriented affair, including a 2 mile walk, 2nd annual car show, inflatable kid zone, food, live entertainment, and

Continued on page 5



In the Spotlight!



Name: Joey Marshall

City & State: Rogers, Arkansas

Age: almost 13! **Grade:** 7th

Favorite School Subject: Physical education and science

Siblings / Pets: I have a brother, Jonathan, who is almost 12. We have four dogs: A german shepherd named Tundra, two cocker spaniels named Precious and Buddy, and a pug named Tia. At my grandparent's farm I have a cat named T.J. and a horse named Joe.

What do you like to do in your spare time? I like to ride my skateboard and play soccer.

Do you have any hints that you could give to other CF kids about their treatments, meds, etc? Don't battle your parents about doing treatments and taking your meds because they help you in the long run.

If you could have one wish, what would it be? Not to have CF!

Other Activities, Awards, or Accomplishments: I enjoy being a team manager for my brother's football team and cheer for him during wrestling season. My family likes to go camping in our fifth wheel and I like to go fishing.

What are your future plans? I want to go to the University of Arkansas in Fayetteville and go HOG WILD!

Meet a CF FAB Member!



Thomas Wilkins lives in Sherwood, Arkansas with his wife Karen and two sons, ages 2 and 5, who both have Cystic Fibrosis. In addition to a busy career as Assistant Vice President of Loan Reviews and Special Assets at One Bank & Trust, N.A., he also serves as our FAB chairperson and is actively involved in the Arkansas chapter of the Cystic Fibrosis Foundation.

Thomas joined the CF Family Advisory Board in order to, "help bring the Care Center and Parents/Caregivers together to help OUR center be the best it can be!" He strongly believes in the power of parents becoming involved and being a vital part of the CF Care Team. "The more informed a parent is," Thomas states, "the better the care is that can be given his or her child. This in turn can help influence the care to all the families that use OUR CF Care Center at Arkansas Children's Hospital."

Corner For Kids...continued from page 3.

A few weeks ago we took a (1) _____ to get into the jungle. Once we got there, we spent (5) _____ looking for a (6) _____ where we could sleep. After we unpacked, we decided to go (8) _____. While we were (8) _____, we ran into a (4) _____ (3) _____. It was the biggest and meanest (3) _____ that we had ever seen. We tried to get away in a hurry, so we decided to (11) _____ as fast as we could. When we finally were far enough away, (2) _____ slowed down a little. All of the sudden, (9) _____ (10) _____ lizards came crawling down a tree and landed on top of (2) _____'s (12) _____. We all (13) _____ and started to throw a (14) _____ at the lizards to get them to go away. Finally, the lizards left and we were able to go our way. While walking out of the jungle, we saw a funny looking (15) _____ who looked just like (7) _____. I couldn't believe it! We took a picture so that everyone would believe us. (7) _____ will be (16) _____. To know that he has a "twin" somewhere out in the jungle. Wow! What a (17) _____ adventure we had!

a special appearance and photo opportunity with SpongeBob. The Hot Springs walk will be on September 6th at the Bank of America in Hot Springs. The Swing for a Cure Gold Classic will be held on October 27th at the Eagle Hill Golf Club in Little Rock. Please visit the website for additional information: <http://Arkansas.cff.org>

Thank You,

Jennifer L. Maune-CFF Executive Director-Little Rock, Arkansas



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 web-sites for some great high-calorie recipes!

<http://www3.nbnet.nb.ca/normap/cfrecipes.htm>

http://familysurvey.com/kid/recipes/cf_recipes/about_cf_recipes.html

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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