



The Cystic Fibrosis Care Center at Arkansas Children's Hospital

Issue 3

Spring 2007

Building Bridges to Create Tomorrows

What's New at Arkansas Children's Hospital?

Bummed about having to stay in your room during your tune up? Wondering just what you're going to do to pass the time? ACH and the Cystic Fibrosis Center staff have been working diligently to make changes that will make your stay as comfortable and entertaining as possible while you are concentrating on getting well. Check out some of the new additions that you might find helpful during your stay:

Cafeteria Service



Tired of getting your tray just as you're hooking up for respiratory therapy? Never fear! The concept is a thing of the past at ACH. Now all you have to do is pick up the phone and dial

4FOOD from your room or your parent can call 364FOOD from outside the hospital to place an order from the cafeteria menu at any time. Want breakfast at 2pm? Not a problem! The 7am to 7pm service offers breakfast all day long and all orders are guaranteed to arrive within 45 minutes. The average wait-time is around 25 minutes, so ordering just before your treatment may be perfect timing. Special perks for CF patients include unlimited ordering of entrees and in-room refrigerators in all private rooms on 4ADO. Be sure to order enough food before the 7pm closing time so that you'll have snacks for the evening, too!

CarePoint Communication System



ACH 4-ADO is piloting the new CarePoint entertainment and communication system that will likely be placed hospital-wide in the near future. The system features a flat-screen television with educational and newly released videos, an internet accessible computer, room-to-room communication systems and more! With the in-room isolation policy in full-force, the system is quite popular with CF patients of all ages. An added X-Box game system is also a favorite. In addition to allowing patients to communicate with one another, x-rays and other medical data can be obtained through the system so doctors can view these with patients. All these features and more are sure to make the new addition to ACH rooms a popular treat for patients, parents, and ACH faculty members.

Physical Therapy Options



For CF patients who require physical therapy, the new in-room isolation policy creates the

need for one-on-one PT in the patient's room, accompanied by some creative and portable options. In room activities can include the "Dance-Dance Revolution" PlayStation game, bicycles or tricycles, and exercise videos. If the weather is nice, patients may even get to spend time doing physical therapy on the roof while watching the helicopter lift from the launch pad!

One-On-One School



CF patients now receive in-room school for one hour three to four times each week. This bedside service provides for a safer teaching environment free from outside contaminants. The hospital teaching staff recommends that students bring work from school or home if the visit is one that is anticipated ahead of time. Be sure to bring along your teacher's contact information such as phone and fax numbers and email address, too.

Child-Life Playtime

The Child-Life Department at ACH has increased its staff to better accommodate the in-room needs of CF patients. Patients may play games, do arts and crafts, choose from a number of videos that may be watched right in the room and much more. Patients are encouraged to bring games and toys from home. The Child-Life staff members and volunteers would be happy to play games and activities that you bring from home, too.



GENETIC SCREENING IN ARKANSAS

At the last CF FAB meeting, our special guest speaker was Ralph Vogel. He is currently serving as Chair of the Arkansas Genetic Services Advisory Committee for the Arkansas Department of Health. Mr. Vogel shared some very important information concerning genetic screenings in Arkansas.

At this time there are only four genetic screenings done for newborns in Arkansas. Starting in July of 2008, Arkansas will have twenty-nine genetic screenings performed on newborns, including a CF screening. All samples will be screened in Little Rock and the results reported to the patient's primary care physician.

There will be a two million dollar start-up cost for the new screening process. Funding has not been specifically appropriated, but the Health Department has been assured that budget will be increased to cover the costs. It is estimated it will take about a year to purchase the necessary equipment and train staff.

Currently the Arkansas Genetic Services Advisory Board is looking for people (including parents) to participate on its committee. If you are interested please contact: Ralph Vogel at his email...

voelralphj@uams.edu



A Note From Dr. Schellhase

I must admit that I am not an expert on living with a person with CF. This distinction goes to parents, other adult family members and siblings of patients with CF. It is appropriate then that each of you share your experiences, both positive and negative, of raising and/or living with a person or persons with CF. You are, after all, the experts in living with individuals with this chronic illness. However, after more than twenty years of taking care of CF patients and their families, I can offer a few comments. I believe that families who adjust best to having a child with CF are open and honest about the diagnosis, are realistically optimistic about the present and future, show love and provide appropriate discipline to not only the child with CF but his/her siblings, involve all family members in the care of the child with CF, attempt to make CF care and life in general fun, encourage learning, take weekends and vacation time together as a family, try to get enough rest and purposely carve out time to do "nothing," seek help if there are relationship problems or excessive tensions within the family, cultivate a life of faith

and learn as much as possible specifically about CF. Family members who can cut each other a little slack, say "I am sorry" and seek and give forgiveness go a long way to improving not only their own lives but setting an example to be followed by their child with CF. I have yet to meet anyone who does all of these things perfectly (including myself), but those families who try to do these things are going a long way to making CF a little more tolerable for themselves, their child with CF and their other children. My advice to you as parents is to seek each other out, share your experiences and remember that you are not alone.



**Join CF patients, caregivers, and support staff on a message board especially for the CF community in Arkansas and surrounding areas : [ArkansasCysticFibrosisFamilies](http://groups.yahoo.com/)
Go to: <http://groups.yahoo.com/> and type in the group name in the search box. Become a part of our online CF community. We hope to see you there!**

Cystic Fibrosis Traveling Tips



Summer is just around the corner! Time for those long awaited vacations you have been planning. If you are a CFer traveling by plane to your vacation destination, below you will find some helpful information to get you there worry-free.



THINGS TO HAVE ON HAND WHEN FLYING:

- **A list of your medications, including both the trade and generic names, with a description of why you need each one (The one that you get now at clinic will work.)**
- **A letter explaining your diagnosis, medication, and equipment can be useful when going through customs, especially if you are traveling with compressor, insulin, or EpiPen needles.**
- **A simple summary of your CF care from your doctor or clinic outlining your status, usual antibiotic combinations for exacerbation, medication summary, and anything else that a doctor may require to provide treatment in a timely manner, in case you become ill.**
- **Your CF clinic's contact information, including names, telephone numbers, and email addresses. Make photocopies of these documents so that you can give a copy to any official who requests it. Keep the originals on your person or in a safe place at all times.**
- **If you are traveling outside the country, find out about the voltage and frequency of electricity and the type of plug adapters and/or voltage converters needed to avoid damaging your electrical equipment.**

Continued on page 3.



- Before you travel to another country, find out if there is a list of CF clinics or hospitals in the area you will visit, in case you need to seek medical attention.

OTHER THINGS TO CONSIDER WHEN FLYING:

- All medicines and medical devices need special consideration on flights. Notify the airline ahead of time of all medications, needles, and devices you are bringing. If you bring injection devices such as insulin or EpiPens on an airplane, you must have a note from your doctor explaining why you have them. You may also be required to bring your own needle disposal unit. Keep all medications and equipment in your carry-on baggage in case you need them on your flight or in case your checked baggage gets lost, and also because temperature-sensitive medications can freeze in the baggage hold. Call the airline ahead to discuss storage solutions. You may be allowed to bring a large carry-on bag to accommodate your needs. Another solution may be "at the gate baggage stow," which is generally for medical items that must be used until boarding. The airline will tell you if any of your medical supplies may be boarded in this manner.
- On the smaller planes, the vest machine will not fit in the overhead bins. You can ask for the equipment to be stowed on-board as you enter the plane so you know it will be the first to be unloaded out of the plane.
- Oxygen levels in airplanes are lower than oxygen levels on land. This usually does not pose a problem unless you have low lung function. If you plan to fly to your vacation destination, your doctor can give you a flight assessment to test your blood gases under normal conditions and then under conditions similar to those on an airplane. He or she will then advise whether it is safe for you to fly without extra oxygen. Some airlines provide oxygen at no cost, some charge a fee, and some do not provide oxygen at all. Most airplanes will not let you use oxygen unless you book ahead.

EXTRA TRAVEL TIPS:

- Pack extra enzymes for high-fat meals you may encounter.
- Take alcohol based waterless hand sanitizer with you,
- If you require refrigeration for medications, be sure to let the hotel staff know, as rental charges are often waived for such usage.
- If you are going to a hot climate, take electrolyte supplementation such as rehydration packets or salt tablets-with plenty of water.
- Many amusement parks or tourist sights have "short-line" entrances, and many others offer free or reduced rate entrance passes to people (especially kids) with certain medical conditions. Inquire about them ahead of time and remember to bring a letter from your doctor indicating that you have CF.

Corner For Kids !

WHAT CAN I DO TO FEEL BETTER?

There are some important things you can do every day to stay healthy and happy. Everything is pretty easy to remember and if you have trouble doing things by yourself, you can always ask for some help. Below is a daily checklist. If you complete everything on the list each day then you are doing a great job helping yourself stay healthy. Remember, a healthy body is a happy body!

- **EXERCISE:** Go running, play a sport, or even jump on a trampoline.
- **EAT 3 MEALS A DAY & SNACKS:** Talk to your doctor if you have trouble with this.
- **EAT FOODS WITH PLENTY OF:**
 - Salt-**Add salt to food and drink sports drinks after exercising.
 - Zinc-**Eat meat, eggs, and fish.
 - Iron-**Eat cereal, meat, dark green veggies, and dried fruits.
 - Calcium-**Eat yogurt, cheese, and drink plenty of milk.
- **MAKE SURE YOU COUGH UP AS MUCH PHLEGM AS YOU CAN:** It is a good idea to keep tissues in your bag or pocket for this.
- **REMEMBER TO HAVE FUN:** Cystic Fibrosis is not **YOU!** It is the disease you have.
- **REPEAT** everything tomorrow to stay happy, and healthy!

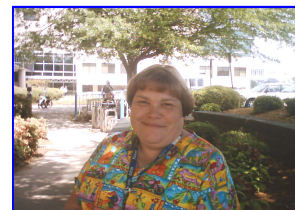


Meet a Member of the Team!

Name: Theresa Hampton

Job: Pulmonary Clinic RN-Team Leader

- **How long have you been working with CF children?** 1 1/2 years
- **What do you like best about your job?** I love the patients and their hugs. I like being part of a wonderful CF Team!
- **Please share with us something funny or surprising that has happened to you while working at ACH.** Once, when a certain patient came, she got very upset about getting her vitals done, especially her blood pressure. I was able to distract her and get her blood pressure but then she needed a flu vaccine. I had my isolation gown and gloves on, and she and I danced, kicked, and twirled while making up a song. While we sang and danced another nurse came in and gave her the flu shot. She did not even realize we gave it. She ended up getting another vaccination shot also, and we repeated the song and dance routine again while it was given. Now every time she comes into clinic she wants to sing and dance (I can never remember the words!) I will do anything to make my patient's visit easier, and see them smile.
- **If you had to choose just one important thing to say to all CF kids, what would it be?** Take your medications daily and set high goals-you can do anything!
- **Please give a brief description/definition of what you do in your job.** I am a Team Leader in the Pulmonary Clinic. I help triage patients, order lab testing, direct patients to where they need to go for testing, keep the flow of clinic going, make sure procedures that need doing get done, and orient new employees.



Cystic Fibrosis Foundation, Arkansas 2007 Calendar of Events

-Great Strides Blytheville Walk-
TBD

-Great Strides Jonesboro Walk-
Joe Mack Campbell Athletic
Complex
Saturday, May 5, 2007

-Great Strides Fort Smith Walk-
Creekmore Park
Saturday, May 12, 2007

-Great Strides Little Rock Walk-
River Market
400 President Clinton Avenue
Saturday, May 19, 2007

-Ozarks Charity Golf Classic-
Shadow Valley Country Club
Rogers, Arkansas
Monday, June 18, 2007

-CF "Catch a Cure" Bass Fishing Tournament-
Arkansas River Murray Park
Little Rock
Saturday, August 11, 2007

-Great Strides Bentonville Walk-
Bentonville Plaza
Saturday, September 15, 2007

-Great Strides Hot Springs Walk-
Bank of America
Saturday, October 13, 2007

-Cystic Fibrosis Golf Classic-
Chenal Country Club
Little Rock
Monday, October 22, 2007



In the Spotlight!



Name: Sadie Medlock

City & State: Prim, Arkansas

Age: 9 **Grade:** 4th

Favorite School Subject: Social Studies

Siblings / Pets: I am an only child. I have two dogs, one cat, four horses, and we also raise rabbits.

What do you like to do in your spare time? Read and also play with my horse, Sugar

Do you have any hints that you could give to other CF kids about their treatments, meds, etc? Always take time for your treatments-it is time well spent!

If you could have one wish, what would it be? To have a brother or sister, and American Girl stuff

Awards and Accomplishments: All A's at PFHA. Myself and three friends raised \$2,027.00 last Christmas for ACH. We call our club the "We Love Kid's Club."

What are your future plans? I would like to become a vet and also raise more money for ACH with the "We Love Kid's Club!"

Fun Food Finds

Trail Mix is easy to carry around with you and will give you energy on-the-go! This will stay fresh in the refrigerator for up to one month.

Ingredients

3/4 cup cashews

1 cup raisins

3/4 cup shredded coconut

1 cup walnuts

3/4 cup peanuts

3/4 cup chocolate Chips

Utensils

1 large bowl

Directions

1. Mix all ingredients in a large bowl.
2. Store in an airtight container and refrigerate.

Makes 10 1/2 cup servings. Take one with you in a baggie, put the rest in an airtight container.

Nutrition Information (per serving):

349 calories, 7 g protein, 24 g fat, 69 mg sodium, 23 mg calcium

Points to consider when contacting the PULMONARY OFFICE:

- If there is an emergency problem-respiratory distress or trouble breathing, coughing up blood, etc.-parents should take the child to the nearest ER.
- If a child is sick, a nurse (not always the nurse for the patient's specific doctor) will call back within 2-4 hours.
- Prescription refills should be called in before the child is out of medicine. Calls will be returned within 24 hours excluding weekends and holidays.
- Routine calls will be returned at the earliest possible time.

Be aware that if a nurse is in clinic, she may not get a message or be able to call back until after clinic ends. Depending on the type of messages received, it may be the next day before she has a chance to call back. There is always a nurse in the office to respond to sick calls. If the parent calls and asks for a specific nurse and is told she is in clinic, it does not do any good to call the clinic and try to talk with her. It is better to leave a message in the Pulmonary Office. If the child is sick, the nurse taking sick calls can handle the call quicker.



How to Reach the CF Team:

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

CF Websites

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

www.uams.edu/pediatrics/cf/default.asp

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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