



Spring 2009

# Building Bridges to Create Tomorrows

## Vest Therapy Gets a Bit Easier

Thanks to national research and current literature, ACH Airway Clearance therapy guidelines have changed. Recently, the ACH Respiratory Care Services Department conducted its annual policy & procedure review. Based on this thorough review, there are several changes that may make life easier for CF patients and families. The new policy regarding *The Vest Airway Clearance System* therapy became effective March 1st and is outlined below:

1. Normal saline alone during Vest is no longer recommended. The majority of hospitals around the country do not use saline. It will also make treatment time easier on patients who have a hard time wearing a mask or holding the mouth-piece for long periods of time.
2. Change the bronchodilator (albuterol or ipratro-

pium bromide) during the Vest treatment from up-draft/nebulizer to a metered dose inhaler (MDI) with a holding chamber before Vest therapy. This change will shorten aerosol treatment time, allow for portable therapy when traveling, and lessen risk of infection from potential nebulizer contamination.



3. Active huffing/coughing should be performed between each Vest speed if the patient is able. Active huffs/coughs should now be done with the jacket deflated and the Vest unit stopped or paused. Deflation of the jacket will allow improved chest expansion for a deeper breath and better cough effort.
4. Each Vest setting (3 speeds) should be done for 10 minutes each totaling 30 minutes.

## Get In Touch with Regional Support Groups



A primary goal of the Family Advisory Board is to provide opportunities for education and support for families dealing with CF in their everyday lives. In order to meet this tremendous need, we would like to invite you to attend your nearest upcoming Family Advisory Board sponsored CF support group meeting. (No patients, please.) Due to strict HIPPA guidelines, the opportunities to reach one another are few and far between. Please contact the committee chairperson listed below so that we can begin to compile a list of CF families in Arkansas who would like to keep in touch with one another as we face the challenges of everyday life. If you don't think you'll be able to attend meetings,

we would still like to add your name to your region's list so that we keep in touch via email.

**Central Arkansas-** Saturday, April 25th, 10 to 12  
**Location:** Victory Baptist School in Sherwood  
**Chairperson:** Angela Anderson, (501) 834-6452  
hganderson@arvest.com

**South Arkansas-** TBA  
**Chairperson:** Laurie Gardner, (870) 325-6686  
lauriemgardner@yahoo.com

**Northwest Arkansas-** TBA  
**Chairperson:** Vickie Marshall  
Marshall.j-v@sbcglobal.net

**Northeast Arkansas-** Saturday, April 25th @ 2PM  
**Location:** Café Buono in Jonesboro, AR  
**Chairpersons:** Brian & Julie Wilkins, (870) 236-0183,  
juliewilkins2001@yahoo.com



## In the Spotlight- Taylor & Justin Satterfield

As you can see, Taylor and Justin Satterfield are just a couple of ordinary kids . . . who both happen to have CF. Big sister Taylor is six years old while her little brother Justin follows close behind at age four. We caught up with the two of them for an interview, and here's what they each had to say:



Do you have any hints that you could give to other CF kids about their treatments or meds?

- Taylor- Play "Go Fish" and it goes faster.
- Justin- My vest is like a bull rider's vest.



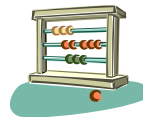
If you could have one wish, what would it be?

- Justin- To have a dog- brown-like "super dog"



What is your favorite subject in school?

- Taylor- Social Studies
- Justin- Math & counting



Tell us about your siblings and/or pets.

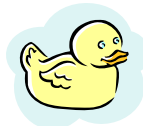
- Taylor- a dog Levi- he is white and black- good personality and he likes to chase us.
- Justin- Taylor is nice. I have a lot of cows, black and white and a dog named Levi.

What are your future plans?

- Taylor- When I grow up, I want to be a doctor of animals.
- Justin- work with my Daddy on his pipeline company

What do you like to do in your spare time?

- Taylor- play duck-duck-goose, chase & tag
- Justin- play with tractors



## A Note From Dr. Com

While focusing on good nutrition, taking usual medications, and using daily airway clearance techniques to improve our patients' lung health, we tend to forget to emphasize the importance of regular physical activity. Multiple studies conducted over the past years suggest that exercise training can improve fitness, help maintain or slow decline in pulmonary function, possibly improve health-related quality of life, and even can extend longevity in children with cystic fibrosis.



Physical training may also be an important part of the managements of diabetes in CF, as exercise improves appetite and contributes to a more positive body image. In addition, regular exercise may delay the onset of osteoporosis by preventing a reduction in bone mineral

density. However, it is not clear how many weeks of training is required to achieve these benefits or what combination of training is required.

Therefore, ACH is implementing a clinical trial on our patients above 6 years of age. Enrolled patients will receive a regular pre-designed exercise program during their hospital stay which will be enjoyable for them. Patients will be asked to continue a home exercise program and the physical therapist will follow their progress in the clinic. Hopefully, we will have a good number of participants and be able to show the benefit of regular physical activity. Regardless, in our center, we will try our best to encourage our patients to be active and physically fit so they can be healthier and happier.





### Meet Crystal Holdeman, Member of the CF Center Family Advisory Board



My husband Steve and I live in Cabot, and have lived here (in Arkansas) for over 2 years now. Our kids are Danielle, age 9 and Adam, age 7 who has CF and 18q- (also known as "Deletion 18Q Syndrome." It means that one of the pair of chromosomes is missing a small piece from the bottom of it.) Adam had numerous issues at birth that required a NICU stay, while the geneticists were looking him over and ordering blood draws, Steve requested that they test for CF. They were quite shocked to have to tell us a couple weeks later that it came back positive. (Steve had an older sister with CF, so we knew it was on his side of the family.)

While technically I'm a stay-at-home mom, I tend to think of myself as Adams' full-time medical care manager. LOL . . . I taught high school physics, chemistry, and mathematics for eight years, up until Adam was 15 months old. Steve used to teach also (social studies), but we found that it was best for him to go back into the Army full-time, allowing me to take care of Adam full-time.

We have moved twice since Adam was born and so have attended three different CF centers. This is the first location where I have heard of a Family Advisory Board and absolutely LOVE the concept. Having that "bridge" between the clinic and the families is very beneficial to our kids' health. As part of the FAB, I also serve on the outpatient committee. Once a month, I attend their meeting and give input on how families would or do feel about issues such as the appointment line and the infection control policy.

Serving on the CF Foundation's educational committee is a great honor for me. I am the only parent on the 15 member committee and so feel an even greater responsibility for it. Already I have reviewed two documents and given feedback. I hope that many of our families will take the opportunities to make your voice heard by participating in surveys and patient/family input opportunities so that we can better serve our CF families in Arkansas.

I also had the opportunity of attending the North American Cystic Fibrosis Conference as our local FAB representative. While the words "North America" are in the title, I can assure you that there were doctors and researchers from all around the world in attendance and presenting. It was awe-inspiring to sit in a room with over 3,800 doctors, researchers, nurses, therapists, etc, and know that they were all there for one purpose: to treat and cure CF. The reason that so many wonderful treatments are available to date is because the Foundation brings these people together to SHARE. And they shared!!!! On the last day, one of the events reminded me of a few things, not the least of which is that most clinicians don't simply walk out the door at 5 o'clock and stop thinking about CF. Much like me when I was a teacher, just because the school day was over didn't mean that I wasn't recognizing new learning opportunities or thinking of ways to enhance my students' lives. Their patients- our kids- are on their minds even when the staff is "off the clock." It takes an amount of dedication to work with young children and the number in attendance at the conference showed just how many are dedicated to helping people with CF.





### Meet a Member of the Team!

Name: Pat Brady, R.N.

Job: Clinical Research Coordinator, Arkansas Children's Hospital

- **How long have you been working with CF children?** I have been working with children with CF for 3 and one half years. Don't tell any of the other Investigators I work with, but CF studies are my favorite!!
- **Tell us a little bit about what you do from day to day:** I am a Clinical Research Coordinator. I work with physicians and PhD researchers to coordinate their studies. I am responsible for preparing and maintaining the regulatory documents, performing or coordinating study procedures and administering study medications and monitoring each child's response to the medication. I also process and ship lab samples all over the country. My job puts me in touch with many different kinds of people from all over the United States and sometimes other countries. I work with a wide variety of ages and diseases.
- **What do you enjoy most about your job?** I like my job because I feel like I am making a difference. I truly believe that research is the key to improving the quality of children's lives. I am so impressed with the amazing kids and their parents I have met. Each new study and new drug is an exciting opportunity to improve the lives of the precious children with CF. That means more to me than anything else.
- **If you had to choose just one important thing to say to all CF kids, what would it be?** If I could give one suggestion to kids with CF, it would be to live your life to the fullest. Do and experience as much as you can. Be brave and courageous.



### Last Minute Medical Tax Tips

Did you know that you may be able to use the cost of medical expenses as a tax deduction?

You can do this if the total medical costs paid by your family in a given year exceed 7.5% of your gross adjusted income that year. Here are some items that you might not know to count toward your medical expenses for tax purposes:

- **Medically Related Transportation:** You can deduct the cost of transportation to and from medical appointments/hospitalizations.
- **Medically Related Lodging:** You may be able to include the cost of lodging (up to \$50.00 per night, per person) related to medical care. Motel costs for a parent while his/her child is in the hospital also qualify. Also included is the case where the child has appointments two days in a row and lodging is required. Medically related lodging is valid only when the primary reason for

the trip is medical and there is no significant element of pleasure involved.

- **Medically-Related Nutritional Supplements and Extra Food to Gain Weight:** If nutritional supplements are prescribed by physicians as medical treatments for CF care, you may deduct them. You may also include the cost of special foods (in case of CF, this would include high fat, high calorie foods) in medical expenses if the need for food is documented by a physician, alleviates or treats an illness, and is necessary above and beyond the needs of a normal diet. The amount that can be deducted is limited to the amount by which the cost exceeds that of a normal diet.

It is important to remember that you must keep receipts and documentation for all items that you are deducting. For information about specific deductions and the kinds of records to keep, go to <http://www.irs.gov/publications/p502/ar02.html#dOe232> You can also call the IRS at (800) 829-1040.



## Inpatient School Tips



Sometimes trying to keep up with school work while in the hospital can be difficult. Here are some things that you can do that will help you to stress less and be right-on-track when you're back home:

- Make a list of your teachers and their contact information. Be sure to include email addresses and fax numbers as these are both great ways to communicate. If you have several teachers, you may wish to include the counselor's information so that he/she can coordinate with teachers and help reduce the number of contacts that you have to make.
- Bring ALL of your books. Whether or not you have assignments, you'll be all set if you go ahead and bring them with you.
- Stay caught up! If you become overwhelmed or struggle, please let your hospital teacher know so that he/she can help.

## Want to help?

Would you like to have an even bigger impact on the health of your child and other children with Cystic Fibrosis? You can do so by becoming a part of our ACH Cystic Fibrosis Family Advisory Board. We need parents of CF patients who are willing to meet quarterly and BE THE VOICE of CF FAMILIES across the state. Board members are from all walks of life and have one common goal in mind. . . to serve to build a bridge between the healthcare team, families and patients with Cystic Fibrosis.

Meetings are held quarterly on Saturdays from 10 to 12PM. If are interested in joining us or if you would like more information, call Mary Jo Chambers (501) 364-6537. Help us to help our children breathe easier!



## News from the Cystic Fibrosis Foundation



Our most fun and family oriented event is quickly approaching! Please join us by forming a CF family team at our Great Strides walk. We are making this request because your help is needed now more than ever!

Recently, the Foundation announced that two key therapies are progressing through their Phase 2 & 3 Clinical Trials—moving them in the right direction for FDA approval. Both of these therapies have the potential to dramatically improve the lung functionality of those living with cystic fibrosis.



This progress is exciting, and it is also costly. To date we have not met our GREAT STRIDES fund-raising commitment for science. We're hoping that each CF family will form a team and get their family and friends to come show support for all our CF patients. Your support is greatly needed so that

we can continue to fund this type of advancement and reach further milestones to a cure. Please take a moment and register your team now by calling 501-371-0233 or by visiting our website at [www.cff.org/greatstrides](http://www.cff.org/greatstrides). We truly need your support.

Thank you,  
Jennifer Maune  
CFF Executive Director

Haskell Anderson,  
CF Dad & CFF Board President



Money buys science.  
Science buys life.  
Those two statements have never been truer than they are today.



## 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 Randag
Clinical Nutritionist:	(501) 364-7533	Heather Hardin
Education/Teacher:	(501) 364-1412	Kathy Robinson
Psychology :	(501) 364-1021	Dr. Anne Stermcock
Social Work:	(501) 364-6537	Mary Jo Chambers

### CFF Great Strides 2009 Walk Dates:



Fort Smith- May 9th  
 Jonesboro- May 16th  
 Little Rock- May 16th  
 Benton- August 29th  
 Bentonville- Aug. 29th  
 Hot Springs- Oct. 17th

## 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 @ [juliewilkins2001@yahoo.com](mailto:juliewilkins2001@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!

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.

### 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."

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