

# CF Connection

**Spring 2008**

**University of Florida Pediatric Pulmonary Center**



## Just for Teens

If your age has moved into the double digits, this bit is for you!

You have entered into a difficult time in your life. You are old enough to be perfectly able to be in charge of your CF care and maybe to really hate being told what to do all the time. If you chose, you could remember all your medications and when they are due. You could take them without any help from your family. You could even call the pharmacy to request refills when you see that you are down to a week's supply. You could do your twice daily airway clearance all by yourself. You could call the pulmonary office when you are having CF health issues like increased cough. You can do all this if you want to and if you work it out with your family.

That's where the hard part comes in. You have to be willing and able and actually DO all the stuff your family has helped you with since you were diagnosed. If your family sees you taking charge, they will know they can leave your care to you. That's the tricky part. Saying you will do it on your own is the perfect first step. It isn't enough all by itself. Until your family actually sees you doing it and doing it right, they won't be able to turn it all over to you.... they love you and

want you healthy! This sometimes causes a lot of conflict between teenagers and their families.

Here's a suggestion: Work with your family or a member of your CF Care team to come up with a list of all the stuff you need to do for your care. That's medicines, airway clearance, diet and solving problems like getting more medicine or calling the doctor's office. Put the list on a daily calendar so you can check off what you do for your care every day. This will help you figure out how to remember everything and will let your family know you are getting it done. Don't cheat! It won't help your health and it won't help you gain family trust that you can handle things. Think about it...

Cindy Capen, MS, RN

If you are 16 years or older, the Adult CF Center at UF invites you and your family to attend the 2nd Annual Patient & Family Education Retreat on June 7th. For more information, please contact Wanda Nichols at 352-846-0750 or [cfcenter@medicine.ufl.edu](mailto:cfcenter@medicine.ufl.edu).

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## We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 4 or e-mail them to [hillajb@peds.ufl.edu](mailto:hillajb@peds.ufl.edu).

Thank you to Solvay Pharmaceuticals for funding the printing of this newsletter.

## CPT, Vest, and Flutter...Oh My!

Being a child with Cystic Fibrosis means that there is a lot going on: school, friends, sports, clubs, and video games. Besides all of that, kids with CF also have to squeeze their prescribed treatments into every busy day. It's no wonder that many children have a hard time completing all of their treatments. In fact, research has shown that on average, many kids complete only half of what their doctors prescribe!

Airway clearance therapy is one part of CF care that is especially difficult for kids and families to fit into their busy lives. One research study asked children with CF and their parents to talk about their experience with airway clearance. These children stated that airway clearance made them feel different from other kids their age, it was sometimes boring, and that they were more willing to do airway clearance when they felt like it was helping them. Another study found that almost 60% of families stated that oppositional behaviors and time management were reasons why it was difficult for children to do airway clearance.

We all know that airway clearance is important for maintaining good health in CF, even though it isn't fun. How can we increase the amount of airway clearance treatments that children do and make it more enjoyable? One research study gave some suggestions. They recommended that children try to relieve boredom by watching a movie, reading stories, or talking with a parent or a friend during airway clearance. These authors also said that some families even play games! Another suggestion was to try to normalize parts of the CF treatment by including friends and siblings—this may help children with CF feel less different from others. Lastly, the authors encouraged families to learn more about why airway clearance therapies are effective—this may make parents and children more motivated to do them!

Merging airway clearance into a scheduled routine often helps families fit the treatment into the day; for example, plan a treatment around a child's favorite TV show. To manage oppositional behavior, some young children benefit from a small reward for cooperating with airway clearance. Giving more responsibility (with parental supervision) to older children for completing their treatment may help them feel more in control of their illness and possibly reduce conflict.

If your family is having a hard time doing airway clearance, ask your CF care team for some help!

Megan Lipe, B.S., Stacey Simon, B.A., and Christina Adams, PhD



### CF Education Day Web Cast

The next CF Foundation's Virtual CF Education Days Web Cast, "The CF Lung Health Anthology: Smoke Exposure, Exercise, Chronic Meds, and ACT" will air at 8 PM on Wednesday, April 30<sup>th</sup>, 2008. Register for the web cast at [www.cff.org](http://www.cff.org) or [www.cfwebcast.org](http://www.cfwebcast.org).

The web cast will be presented in an exciting new format - four different segments (approximately 15-20 minutes each) will each be presented by an expert and highlight information about specific topics. You can choose to watch all or some of the individual presentations, which will be aired back to back from the time the broadcast begins.

The Web cast will be archived by topic, so if you can't tune in live, you'll still be able to watch them at your convenience.

## Are You Ready for the Heat?

With the hot and humid Florida weather right around the corner, it's time to make sure you are getting enough salt (sodium) and fluid. People with CF lose extra salt through their sweat and are at higher risk for salt depletion and dehydration.

Dehydration can happen quickly and can be dangerous. Some signs of dehydration are increased thirst, muscle weakness, headaches, fatigue, dizziness, and fever. The most severe result of salt depletion and dehydration is heat stroke, which can lead to loss of consciousness, seizures, and kidney failure.

It's important to eat plenty of salt and salty foods and drink enough fluids to prevent dehydration. Choose foods high in salt (sodium) and be generous with the saltshaker. People with CF who are active in sports or play outside in the hot weather have even higher salt and fluid needs. Sports drinks such as Gatorade® or Powerade® do not have enough salt for a person with CF during times of increased activity, so it is recommended to add 1/8 teaspoon of salt to every 12 ounces of sports drink.

### Foods High in Sodium & Calories

- ✓ Pretzels with cheese dip
- ✓ Salted bagel with cream cheese
- ✓ Ritz crackers with cheddar cheese
- ✓ Dry roasted peanuts
- ✓ Nachos
- ✓ Ham & cheese sandwich with mayo

Jen Hillan, MSH, RD, LD/N

## “Transitioning” to Adulthood

What will you be doing in three years? In five or ten years? It may be hard to envision, but thinking about your future is important because it affects the choices you make now. The gradual change from childhood to complete independence is often called the “transition” to adulthood. The teenage years are transitional years—a teenager is no longer a child but is not quite an adult. It is also important for parents of young children and pre-teens to be thinking ahead about their children's futures. This sets the stage for children to start thinking about future goals. It also helps children develop routines and habits. Responsibility, study skills, self-care, discipline and organization (as well as the ability to enjoy hobbies, play and have fun!) are just a few skills that must start in childhood.

For a teenager, transition involves thinking about where you will want to live, and with whom; what you want to do in terms of school or work; your hobbies, interests and social life; and your healthcare. It also involves skills like managing money, making appointments, planning and organizing. Beginning to think about career interests will help you decide how much schooling you need and what classes to take. Identifying where you want to live and with whom will help you figure out how much money you'll need to make. Knowing what kind of social life you like will help you know how to spend your time. If you like to be around a lot of people, you may want to join some clubs or after school activities. If you prefer to be alone or with just a few people, you may want to find some more solitary activities.

We'll be talking more with you about transition as time goes on!  
Susan Horky, LCSW

# University of Florida Pediatric Pulmonary Center

## Family Corner

### From the Adult Side...



Today I had a chat with Chelsea who transferred to the adult CF program about a year ago. Chelsea had been a patient in the pediatric center for a long, long time (I met her when she was just days old), so I wanted her opinion of the differences between the peds and adult clinics. Her first response was "I like it." She likes that the adult team members automatically talk to her, not her Mom. "They treat me like an adult. They talk to *me* more."

She feels like she is a participant in the treatment plan and that the team members care how she feels when evaluating her response to treatment. "They look at the numbers, but they listen if I say I don't feel like I am ready to go home." She says they don't like to keep patients in the hospital a long time and so they use home health care more than the pediatric team does. When she goes into the hospital, she is on an internal medicine service with pulmonologists consulting. She says the pulmonary doctors are in and out "all the time" and if she has a problem, she just tells them about it.

She thinks clinic is about the same and there are even some familiar faces since Jennifer Hillan provides nutrition services and Dr. Stalvey provides diabetes care in both pediatric and adult programs.

So I said, if you were to offer words of encouragement to someone who will be moving to the world of adult CF care, what would you say? Her reply? "It's not a bad thing. You get a new way of looking at things."

From my side...it is really hard to part with "kids" and families we've known for years but it is a wonderful thing to see our kids becoming adults!

Cindy Capen, MSN, RN

Pediatric Pulmonary Center  
University of Florida  
Health Science Center  
P.O. Box 100296  
Gainesville, Florida 32610-0296

**Phone:** 352-273-8380

**Toll Free:** 1-888-4UF-SHANDS

**Fax:** 352-392-4450

#### Medical Staff:

Sarah E. Chesrown, MD,

Interim Division Chief

Mary H. Wagner, MD

Pamela Schuler, MD

Daniel Torre, MD

Thomas A. Horsman, MD

Sreekala Prabhakaran, MD

Rafael Cilloniz, MD

Lauren Evers, ARNP

#### Pharmacy:

Leslie Hendeles, PharmD

#### Nursing Staff:

Cindy Capen, MSN, RN

Rhoda Reed, SRNS

#### Nutritionists:

Ellen Bowser, MS, RN, RD

Jennifer Hillan, MSH, RD, LD/N

#### Social Worker:

Susan Horky, LCSW

#### Office Staff:

Brenda Martin

Tina King

Lisa Harvey

Nita Newell

#### Family Consultants:

Angela Miney—[aminey@ufl.edu](mailto:aminey@ufl.edu)

Robin Muetzel—[rmuetzel@ufl.edu](mailto:rmuetzel@ufl.edu)