COOK CHILDREN'S
CYSTIC FIBROSIS CENTER

FORT WORTH, TX.

# COOK CHILDREN'S CYSTIC FIBROSIS NEWS

VOLUME VIII FALL 2012

**The Cystic Fibrosis Center at Cook Children's Medical Center is one of more than 115 accredited CF centers throughout the nation. These centers are accredited by the Cystic Fibrosis Foundation, a non-profit organization founded in 1955 dedicated to funding research to find a cure for CF and improving the quality of life for people with the disease.**

## INSIDE THIS ISSUE:

## It's that time again!

Many children with CF find that attending school with their friends prepares them for the future. If your child goes to school, it is vital to work with the school to help meet your child's daily health needs. To do this, you may need an ***Individual Education Plan (IEP)*** under the ***Individuals with Disabilities Education Act (IDEA)*** or a 504 plan under Section 504 of the Rehabilitation Act of 1973. The IDEA is a federal law that makes public elementary and secondary schools give free and appropriate education to children with disabilities. Section 504 is a federal law that prohibits discrimination against a person because of a disability by any group that gets federal funds. An IEP or 504 plan outlines how absences or medical treatments, like taking enzymes, will be managed by the school. An IEP or 504 plan can be requested for many reasons.

To get an IEP or 504 plan, or a review of your child in preparation for one, contact your child's school. It is best to do this at the start of each school year. Contact the teacher, administrator or school nurse, and ask for an evaluation of your child under the IDEA or Section 504 of the Rehabilitation Act. Your CF care center has a sample letter that your CF doctor can use to write to the school to explain how CF affects your child and to identify some school accommodations that may help. Your CF care team also may have ideas about how the school can help you meet your child's learning and health care needs.

Not all parents want to have a written IEP or 504 plan. Instead, you may have a verbal agreement with the school so your child can take medicines at school. But, without a written plan, the school does not have to honor the agreement. Under the IDEA, students ***qualify for services*** if their disability affects their ability to learn. Missing school is one way an illness can affect your child's ability to learn. This may qualify your child for services, like a tutor, when your child is absent from school due to an illness. But, you need to have an IEP or 504 plan in place *before* your child is absent because of an illness. If you do not, it may take weeks to get help from the school. If a plan is in place before your child gets sick, the school can start the plan and get a tutor in a few days when you tell the school that your child is absent due to illness and will need help.

Once a student qualifies for services, the school will hold a team meeting with the family to make an IEP or 504 plan. The plan says what the school will need to do to meet your child's needs. You, the school's IDEA coordinator, the teacher and people who know your child's needs should attend the team meeting. Students age 14 and older often are encouraged to attend. Bring a copy of the letter from your CF doctor and any other records that show why your child needs certain accommodations. If the IEP or 504 plan does not meet your child's needs, do not sign it. You have the right to stop and reschedule the meeting if you need to learn more about your child's needs before a plan is done. Your CF care center has a copy of a sample plan if you would like help in making an IEP or 504 plan. The IEP or 504 plan should be reviewed at least once a year to see if changes are needed.

The school may not agree that your child is qualified for services under the IDEA. It may state that CF does not affect the child's ability to learn. Then, you can ask that your child be evaluated under Section 504 of the Rehabilitation Act of 1973. Section 504 requires the student to have a disability that ***substantially limits*** a ***major life activity***. Many people with CF qualify for services because their ability to breathe or digest food is limited. So, Section 504 should give your child the changes needed to benefit from school.

http://www.cff.org/UploadedFiles/LivingWithCF/AtSchool/SchoolAndCF/Day-to-Day-School-and-CF.pdf

## Elementary, Middle School and High School IEP Suggestions

1. Give time during school day to take medicines or do airway clearance therapy.

2. Adjust school rules to allow child to take own medicines, like pancreatic enzymes.

3. Have plan to get homework or tutor when child is ill or in the hospital.

4. Give audio or video tapes of missed classes.

5. Adjust or waive attendance rules.

6. Give access to private bathroom, perhaps in a nurse's office.

7. Don't limit access to bathroom or water.

8. Have a school medical emergency plan.

# College, University and Vocational Training

After finishing high school, some students with CF may decide to get a college and/or university degree or learn a vocation. The joy and pursuit of learning should be encouraged. People with CF should seek new options to learn and plan for their future. Colleges, universities, vocational training centers and other places of higher education that get federal funds are covered by Section 504 and cannot refuse to admit a qualified student solely because the student has a disability like CF. Most colleges and universities have an Office for Students with Disabilities that can help students get accommodations that are needed. If a school of higher education has no such office, there should be someone in the school's administration who helps students obtain accommodations because of a disability. Call the school to learn about the help available for students with disabilities. You also can meet with someone at the school to talk about your concerns. You do not have to tell the school that you or your child has CF. But, you will need to tell them about CF if you request accommodations that you or your child needs because of CF. If asking for accommodations, get a written agreement with the school that lists the changes to be made. You may request an accommodation at the school at any time. If you or your child leaves home to attend school, contact the CF care center nearest to the school at the beginning of the school year so they can help you with any treatment for health problems during the year. Your CF care team can help you determine the needed accommodations and work with the school.

## College IEP Suggestions

1. Provide student certain type of dorm room, like a private room, or room with private bathroom or air conditioning, if needed because of health.

2. Change the student's required number of class hours per semester. However, this change could affect the student's health insurance coverage.

3. Change class attendance rules, giving student other options like Internet, video, etc.

4. Change student's physical education requirements.

5. Plan to change project due dates or test dates if student is absent due to illness.

6. Plan to give student notes from class or class audiotape if absent due to illness.

7. Give student a chance to finish coursework after the course has ended, if much of the semester was missed due to illness.

8. Give on-campus housing or parking.

# Pneumococcal Vaccine Prevnar®/ Pneumax®

Infection with *Streptococcus pneumoniae* bacteria can make children very sick. It can cause pneumonia, blood infections and meningitis, mostly in young children. (Meningitis is an infection of the covering of the brain.) Although pneumococcal meningitis is relatively rare (less than 1 case per 100,000 people each year), it is fatal in about 1 of 10 cases in children. Pneumococcal meningitis can also lead to other health problems, including deafness and brain damage. Infections with this organism are not common in people with CF but vaccination provides additional protection with very few side effects.

Children should be vaccinated in the first year of life against pneumococcal disease in their PCP's (Primary Care Provider) office with Prevnar®. This vaccine is especially formulated to protect children against the most common strains of s. pneumoniae. Prevnar® is recommended as a series of 4 doses, one dose at each of these ages: 2 months, 4 months, 6 months, and 12 through 15 months.

Some cases of pneumococcal disease have also been caused by strains not included in Prevnar®. People with CF should be protected against those strains by a second vaccine called Pneumovax®. This vaccine can be given after 2 years of age when needed. When and how often to give Pneumovax® varies so please discuss with your CF Physician. Since primary care offices may not offer these additional vaccinations, the CF Clinic can provide Pneumovax® to patients as needed.

Ref: CDC info sheet, National Network for Immunization Information

## ***FLU VACCINE***

This is a reminder that all CF patients are highly recommended to receive the FLU VACCINE. We will send out an email when the vaccine has arrived in our clinic. Please be sure to contact us via phone if you have already received this vaccine. If you have NOT received the flu vaccine please schedule an appointment any day of the week.

** It is important that CF patients as well as family members also receive their flu vaccinations.

# Cook CF Patient Spotlight!

## Kelsey Shingledecker

1.Tell us a little about yourself…

I'm 20 and attend Texas A&M in College Station where I'm majoring in Psychology. My best friend is my snake Simone. My favorite movie is a toss-up between Pride and Prejudice & Scott Pilgrim vs. the world (depends on my mood). I modeled for Cover Girl for my Make-A-Wish. I never do anything half way.

2. When were you diagnosed with CF?

At six weeks old

3. What are some of your favorite hobbies/ activities?

I LOVE COOKING!!!! I make a mean mac and cheese :) I love playing video games (I'm a Pokémon nerd lol) and I knit on occasion. Simone and I watch chick flicks on Saturday nights. I'm actually quite boring in that respect. I was also on my high school dance team for four years.

4. What are some of your favorite foods?

3 words: RED VELVET CUPCAKES! I love them to death (I once gained 14 lbs in the hospital because I ate two dozen of them) I also love cereal (my favorite is coco pebbles).

5. How do you balance life with CF?

It's hard to be honest, I have a really great support system, and you just have to take it one day at a time and never ever let it slow you down. You gotta make time for treatments just like you have to make time for everything else.

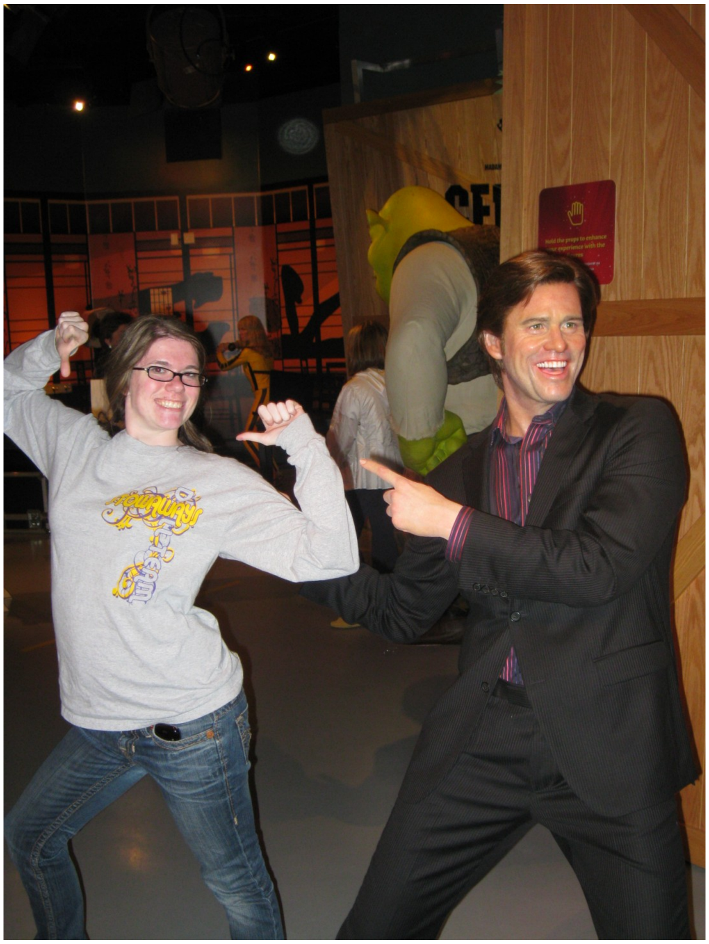
**6. Tell us something unique about yourself?**

I want to get a purple rose tattoo when I turn 21, hopefully the first of many, if I don't chicken out. I used to have green hair & purple hair (purple is my favorite color).

**7. What are your future goals?**

Get my PhD in psychology (don't know which field yet) move to New York (maybe working for a fashion stylist or Better Homes & Gardens in their test kitchen) Getting my own show on Food Network is my absolute dream. I know it sounds strange for someone to get a PhD in psych and then dream of kitchens. I want to help people either through food or therapy.

**8. What's a piece of advice that you might give to someone else with CF?**



If you use your illness as an excuse you've already lost (unless it's for a good reason :]) oh and never do anything half-way, go big or go home. Yes, you will be sad and things may not be fair at times, but you just got to pick yourself up and continue on. My internal motto is "Don't waste your energy worrying about things you can't fix; focus on what can be fixed."

**9. How long have you been a patient at Cook CF Clinic?**

I moved here in June, 2006.

**10. What do you like best about Cook?**

The docs, nurses, picc team, everyone is really super nice. I'm going to miss them— when I go to the adult center at Harris. I love j-tips ( they're used for blood draws on babies) they make picc lines almost painless.

# Cook CF Center Research Studies

Our CF center is currently participating in several research studies as part of the quest to make CF stand for Cure Found:

- A study testing the effectiveness of a treatment plan to eliminate MRSA in patients that are newly diagnosed with MRSA lung infection (STAR-too).
- An infant nutrition study for our CF newborns (BONUS).
- A study to determine the effectiveness of TOBI powder in CF patients with Pseudomonas lung infection (TIP 4).
- A new Vertex study to determine the effectiveness of Kalydeco in CF patients with the R117H CF gene mutation (Vx 110 also called “Konduct”).

Several additional studies are in the planning stages for our Center. We hope to be selected as a research site for the upcoming Vertex 809/770 study for patients with 2 copies of the delta F508 CF mutation which will start up sometime this winter.

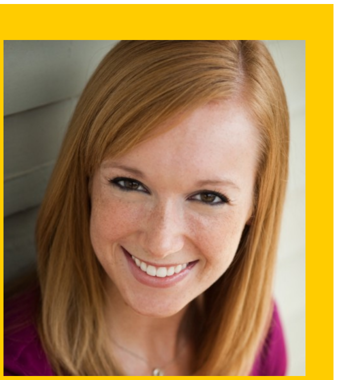
If you would like more information or have questions about research at our CF center please contact:

Sara Scott, RN MA CCRC, Sr. Clinical Research Coordinator

One of the CF Center Coordinators

Your CF Doctor

## Welcome!



**Julie DuBois, RD LD**
**Pulmonary Dietitian**

Julie was born in Washington D.C. but claims Fort Worth as her hometown. Julie is a former professional ballet dancer, having danced with Texas Dance Theatre, Tulsa Ballet, and Orlando Ballet prior to attending Texas Christian University for her degree in nutrition. Julie still performs as a guest artist for ballet companies in the DFW Metroplex and also teaches boot camps through Camp Gladiator. Her hobbies include: playing with her husky Bailey and staying active with ballet, bootcamp, and other adventurous hobbies, such as sky diving.

## ***Reminder***

If your child will be hospitalized while he or she is on the inhaled medication Cayston, please bring your Altera nebulizer machine, Cayston medication and neb cups as the hospital is currently in short supply until around Sept 4th.

Thank you!

## Take some time for yourself!

- **Take time to relax** daily and learn how to regulate yourself and de-stress when you start to feel overwhelmed.
- **Keep a journal.** Write down your thoughts and feelings. This will give you perspective and serve as a way to release strong feelings.
- **Talk with someone** to make sense of your situation and your feelings.
- **Feed your spirit.** Pray, meditate, or do another activity that makes you feel part of something greater.
- **Explore your beliefs**, even if you don't consider yourself religious. Try to find meaning in your life and in your role as a caregiver.
- **Watch out for signs of depression and anxiety**, and get professional help if needed.
- **Stay social.** Make it a priority to visit regularly with other people. Nurture your close relationships.
- **Do things you enjoy**. Laughter and joy can help keep you going when you face trials, stress, and pain.
- **Maintain balance in your life.** Don't give up activities that are important to you, such as your work or your hobbies.
- http:://www.helpguide.org/elder/caring_for_caregivers.htm

## Share Your Recipe!

Recipes are still being accepted for the **CF**Chef Online Cookbook.

From protein shakes to pancakes, we invite you to submit your favorite CF-friendly recipe. Recipes will be evaluated by a registered dietitian for nutritional value before they are posted to the **CF**Chef Online Cookbook.

**The Winter Holiday Recipe Contest** Submission Period begins on July 20, 2012, and ends on September 14, 2012 at 11:00 AM ET.

**The Spring Holiday Recipe Contest** Submission Period begins on September 14, 2012, and ends on December 17, 2012 at 11:00 AM ET.

http://www.chef4cf.com/recipe-contest/submit-recipe.html

CookChildren's

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**Cystic Fibrosis Center**

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**Making CF stand for "Cure Found"**

## Pediatric CF Center Staff:

Center Physicians: **James Cunningham, MD– Center Director** (Nurse: Stacy), **Nancy Dambro, MD– Center Director** (Nurse: Charity & Karen), **Maynard Dyson, MD** (Nurse: Stacy), **Sami Hadeed, MD** (Nurse: Sharon), **John Pfaff, MD** (Nurse: Tiffany), **Karen Schultz, MD** (Nurse: Paulette)

## Adult CF Center Staff:

Center Physicians: **John Burk, MD– Adult Center Director, Steve Davis, MD, Stuart McDonald, MD, Cyndy Roger, ACNP-BC (**Nurse: Sofia, adult nurse and newborn screening)

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|---|---|
| CF Coordinators: | |
| Janet Garbarz, Carrie Stradley | 682-885-6299 (#6) |
| Dietitian: | |
| Staci Brummett, Cristina Puga, Julie DuBois | 682-885-7496 |
| Respiratory Therapists: | |
| Deanna Pinckney, Alex Rasmussen, Crystal Thompson, Cindy Corne | 682-885-4189 |
| Child Life Specialist: | |
| Leah Fox | 682-885-4892 |
| Social Services | |
| Kate Ousley | 682-885-2863 |

# Cook's Corner: Recipe for Success

## Enchilada Casserole

### Ingredients

- 1 (10.75 oz.) can of cream of mushroom soup
- 1 (15 oz.) can of enchilada sauce
- 2 c. cooked chicken breast, diced
- 1 c. cheddar cheese
- 3½ c. tortilla chips, crushed

### Directions

1. Preheat oven to 375 degrees.
2. Place all ingredients in bowl and mix well.
3. Pour the mixture in greased 9 x 13 pan.
4. Bake for 25 minutes.

Nutritional Information per 2 cup serving:

681 calories

1977g sodium

368 g calcium

51 g protein