

COOK CHILDREN'S CYSTIC FIBROSIS NEWS

VOLUME X

SPRING 2013

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:

CFF New Infection Prevention & Control Policy 1

Social Media & CF 2-3

CF Patient Spotlight-Emily 4-5

New Staff 6-7

Staff Directory Cook's Corner 8

CF Foundation Updates Infection Prevention and Control Policy

The Cystic Fibrosis Foundation recently updated its Infection Prevention and Control Policy for all Foundation events, meetings and offices to protect the health of people with cystic fibrosis.

The Foundation took this step based on increasing medical evidence of a greater risk that people with CF could spread destructive germs to others with CF, which may lead to severe or worsening lung disease. The new policy reflects the advice of leading CF medical experts and published medical research.

The key elements of the Foundation's policy are:

Indoor events: At any Foundation-sponsored indoor event or meeting, including gatherings such as chapter committee meetings, only one person with CF may be present and he or she will be designated in close consultation with event chairs and key event volunteers.

Outdoor events: At Foundation-sponsored outdoor events or gatherings, people with CF need to maintain a distance of at least 6 feet from each other.

B. cepacia: Under no circumstances shall individuals who have ever had a confirmed positive sputum culture for *Burkholderia cepacia* (*B. cepacia*) complex attend any Foundation events, meetings or offices.

"We understand that these changes may be difficult for many in our community," said Robert J. Beall, Ph.D., president and CEO of the Foundation. "However, we want to be sure that we are doing all we can to reduce the risk of cross-infection among people with the disease. The health and well-being of people with CF is our top concern — it is at the heart of all we do."

The Foundation is expanding its use of teleconferencing and live videocasts to help make it possible for people with CF to participate in indoor Foundation events and meetings and is exploring other new technologies to engage people with CF in all of its activities.



Social Media and Cystic Fibrosis:



If you haven't heard of this new app that is taking over smart phones and connecting people from all over, chances are your teens have! The app is a mash up of Twitter and Facebook. Users create a username and post pictures of anything and everything. Users can follow one another and then comment and "like" individual's photos. When posting a photo users can include a "hashtag" to describe or categorize the photo. For example: *#lovethebeach* *#Christmas* *#graduation* *#sweet16*. Users can then search photos by hashtags to see what other users have included under specific *#hashtags*.

So what does this have to do with CF, you ask? One of my favorite hashtags to tell our teens with CF about is *#cfshoutout*. Under this hashtag you will find pictures of various people doing their CF care, quotes that pertain to CF, and much more surrounding the world of CF. It is an awesome way to informally connect with other people who deal with similar life challenges. The best part is that you are as involved as you want to be. You can simply browse the pictures or chose to go as far as commenting and connecting with other users.

It can be a beneficial tool for parents to connect with other parents but equally as important, a tool for teens to connect with other teens! A chronic illness can leave anyone feeling isolated or different and then you add to that the fact that with CF you can't even be around the only people in the world who will truly ever understand you. The world is becoming smaller and more connected each day particularly through social media such as Instagram. What a great way to help teens with CF be connected to other teens and have an opportunity to express their thoughts and feelings surrounding CF.

Social Media and Cystic Fibrosis, continued



Today YouTube is used for practically everything! Some of the most popular uses are: replaying sports highlights or TV clips, a means to skyrocket a musicians career (Justin Bieber), teaching of how-to skills, and so much more. Recently we discovered that patients and their families use it for many things pertaining to CF, including: education, fundraising, and awareness. Therefore, we thought we would share some of our favorite videos about CF.

Clinics Top Picks:

1. "Helping Kids with Cystic Fibrosis Succeed in School" <http://m.youtube.com/watch?v=EASUbdXnHrI&feature=m-ch-fea>

We repeatedly hear from families how it can be difficult to explain what CF is and what their child needs may be in the classroom. It is often hard to explain cystic fibrosis to someone who isn't living with it, where do you even begin? This video does it for you! It is an awesome way to start a conversation with your child's teachers about what CF is and how they can help your child succeed!

2. "Cystic Fibrosis Foundation- Adding Tomorrows" <http://www.youtube.com/user/CysticFibrosisUSA>

This video is great for general awareness. Depicts real people living with CF describing their daily routines. It also discusses kalydeco and the research that the cystic fibrosis foundation supports.

3. What is cystic fibrosis? Animation <http://www.youtube.com/watch?v=FMAOEOMLoUE>

Explaining CF to affected children, their siblings, and their friends can often be a challenge. This video breaks down the explanation in age appropriate terms. It also has cute simplistic animations to depict things like mucus and germs.

Cook CF Patient Spotlight!

Emily Williams

1. Tell us a little about yourself...

Emily is a vivacious, strong willed, energetic, 4 year old. She has two big brothers she adores and tries to keep up with.

2. When were you diagnosed with CF?

In utero through an amniocentesis at 20 weeks. We (her parents) found out we were both carriers when I was pregnant with her oldest brother. We scheduled the genetic test to see if she had CF.

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

Emily loves school, playing with friends, gymnastics, singing and anything and everything to do with princesses.

4. What are some of your favorite foods?

Pork chops, her daddy's pancakes, and frosted sugar cookies

5. How do you balance life with CF?

It's just part of her routine. She has never known what it's like to not have CF, so to her it is normal. Breathing treatments and chest PT are just a scheduled part of her day like school, naps, meals, etc.



6. Tell us something unique about yourself?

Emily is very adventurous. She loves roller coasters, tubing behind a boat, riding horses, floating the river and feeding alligators. She does not shy away from ANYTHING! Also, she was in her first CF drug trial at 4 months old for hypertonic saline. She tolerated the treatment well and has been on it ever since.

7. What are your future goals?

If you were to ask her right now, she'd say to grow up to be Princess Ariel and marry Prince Eric, from Little Mermaid. I really think she can do and be anything she wants to be. We are trying to teach her that CF is just a part of her life, not it's totality. CF may add additional obstacles and challenges, but it does not define her or limit her.

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

Keep doing what your good at and push yourself to your limit, and even though you have CF, just like me, you can do it, just like me!

9. How long have you been a patient at Cook CF Clinic? 4 1/2 years

10. What do you like best about Cook?

The staff. Everyone is so caring and compassionate. They take their time and make sure all our questions are answered. Emily especially loves Alex, the Child Life specialist and all she does to make visits easier and less scary. Princess apps on the iPhones are greatly appreciated!



Welcome New Staff!

Shonda Thompson, RRT

Respiratory Therapist

I was born and raised here in the Fort Worth area. I graduated from O.D. Wyatt High School and I received my Respiratory degree from ATI Career Institute in Dallas, TX. I enjoy reading and road trips! I have one son, Anthony who is 14 years old. I have been married to my husband, Reco for two years. Our newest addition to the family is Bruiser who is an 8 month old Yorkie.



Amy Wilson, LMSW

Social Worker

My family is from Dallas/Fort Worth. I grew up in Grand Prairie and the Cedar Hill areas. I attended UTA for both undergrad and graduate school. When I am not with my work family, I enjoy playing with my three year old son. I also love spending time with my family, going to the lake, biking, cooking and painting.



Trudy Morris, RN, CRCC

Clinical Research Nurse

I was born in Ogden, Utah (my dad was in the Air Force), but I have lived in Texas since I was an infant. I received my BSN from the University of Texas in Arlington. Interest/hobbies: antique shopping, decorating, reading. I have two children Allie age 20 and Jacob 22 years old. I worked on the CF floor for 8 years and that is where I established CF as my "first love".



New Staff, continued

Lisa Boyd, RN

Dr. Das Nurse

I am from the DFW area. I grew up in the Burleson/Joshua area. I went to school at Tarleton State University in Stephenville. I like to travel whenever I can, enjoy going to Texas Rangers baseball games and cooking. I have been married for the past two years. I have a 1 1/2 year old Maltese named Bella.



Dr. Das, DO

Pediatric Pulmonologist

I am from Houston. My undergrad was at A& M. I went to medical school at the University of North Texas Health Science Center. My residency was at Texas Children's Hospital and my fellowship was at Baylor College of Medicine/Texas Children's Hospital. I moved back here in October, 2012. I like all things sport related...playing sports, following sports teams... (Go Aggies!). I also enjoy playing volleyball, racquetball and basketball. I am enjoying getting to know the DFW area again.



CookChildren's

Cook Children's Medical Center Cystic Fibrosis Center

Pulmonary Services
1500 Cooper Street
Ft. Worth, Texas 76104-2724
Phone: 682-885-6299
Fax: 682-885-1090
Email: www.cookchildrens.org

Making CF stand for "Cure Found"

Pediatric CF Center Staff:

Center Physicians: **James Cunningham, MD– Co-Center Director** (Nurse: Stacy), **Nancy Dambro, MD– Co-Center Director** (Nurse: Jennifer & Karen), **Maynard Dyson, MD** (Nurse: Stacy), **Sami Hadeed, MD** (Nurse: Sharon), **John Pfaff, MD** (Nurse: Jessica), **Karen Schultz, MD** (Nurse: Paulette), **Shailendra Das, DO** (Nurse: Lisa)

Adult CF Center Staff:

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

CF Coordinators:

Janet Garbarz, Carrie Stradley 682-885-6299 (#6)

Dietitians:

Staci Brummett, Cristina Puga,
Julie DuBois 682-885-7496

Respiratory Therapists:

Deanna Pinckney, Alex Rasmussen,
Crystal Thompson, Cindy Corne, Shonda
Thompson 682-885-4189

Child Life Specialist:

Alex Steward 682-885-4892

Social Services

Amy Wilson 682-885-2863

Cook's Corner: Recipe for Success

Broccoli Salad

Ingredients

- 3 c. bite size broccoli
- 2/3 c. golden raisins
- 1/4 c. chopped red onion
- 1/2 c. walnuts
- 15 slices of cooked bacon, crumbled
- 2 Tbsp. sugar
- 3 Tbsp. red wine vinegar
- 1 c. mayonnaise

Directions

1. In large bowl, toss broccoli, raisins, walnuts and bacon.
2. In a separate bowl, whisk together sugar, vinegar, and mayonnaise.
3. Pour mayonnaise mixture over broccoli and toss to coat.



Serves 6

Nutritional Information (per 3/4 c. serving)

524 calories, 46g fat, 11 g protein, 670 mg sodium, 42mg calcium