



FALL 2015

Cook Children's Cystic Fibrosis Newsletter

Mobile Apps for Cystic Fibrosis

CF related apps are the hot new trend. From assisting with medication schedules to kid friendly games, you will find a wide variety of apps to help manage cystic fibrosis. Check them out...

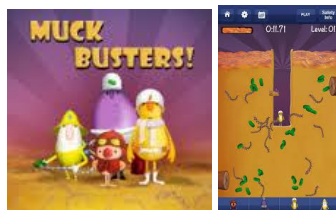
1. **Medisafe** is the leading medication manager and pill reminder. If you need to organize and/or can't remember to take your meds, this is the app for you! Get it now

<http://bit.ly/1qdv4Nd>

For more information visit,
www.medisafe.com



2. **Muckbusters**: Utilize the unique abilities of this colorful team of characters to help you get rid of sticky slime and enemies. The game also includes a way to help keep track of your day if you have CF



3. **My Fight Against Cystic Fibrosis**: A Cystic Fibrosis app 100% designed, developed, and programmed by a CFer. The mission of this app is to provide the CF community with a useful tool and resource to help fight Cystic Fibrosis.



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4. **My CF (Cystic Fibrosis)**: This is an app for individuals and families of individuals with Cystic Fibrosis (CF) to help you keep track of your CF ! Parents can use it to keep track of their child's health as well



More mobile apps continued on the next page..

Touch-A-Truck, DFW

All proceeds support the Cystic Fibrosis Foundation

In efforts to adhere to the CF Foundation's guidelines regarding infection control, please let the admission table know if you or your child has cystic fibrosis. You will receive a different color paper wrist band upon entering the event. Per infection control guidelines, patients who culture B. Cepacia may not attend the event. Thank you for your understanding

Like
Touch-A-Truck, DFW

TOUCH A TRUCK
DFW

Rolling Into Town
SUNDAY, OCTOBER 18, 2015
11 A.M. - 3:30 P.M.
\$5 PER PERSON

BIRDEVILLE FINE ARTS/ATHLETICS STADIUM PARKING LOT:
9200 MID-CITIES BLVD, NORTH RICHLAND HILLS, TX 76180

Explore community vehicles, trucks, machinery - anything with wheels! Meet the hometown heroes that protect, build, and serve our community while enjoying a Kid Zone, Raffles, Community Booths & Food Trucks.

Star-Telegram FORT WORTH

Bruckner's, frazier, Texas Dental Resources, ARGOS, SHIFTADMIN, RED

For Questions or concerns: touchatruckdfw@gmail.com

CF Related Mobile Apps



Continued...

5. **CF-Notebook:** Provides a single place to keep track of all the CF related needs; Meds, Meals/Snacks, Exercise, ACT, Blood Sugars, Appts, Contacts, Refills and Weight.



6. **Bacteria Battle:** Look alive, soldier !!! The body is under attack !!! Cystic fibrosis is affecting the lungs making it hard to breathe !!! As a soldier in the antibiotic army, your mission is to hunt down bacteria and destroy them before they cause too much trouble. Slash, run and jump to destroy those pesky bacteria!!!



For other great CF high-calorie recipes check out:
www.chef4cf.com

Cook's Corner: Recipe for Success

Yummy Baked Potato Soup



Winning Recipe!

Serving Size

6 servings
 Calories: 640 calories per serving
 Fat: 36 g
 Sodium: 820mg
 Protein: 18 g
 Calcium: 285 mg

Ingredients

1/2 pound bacon
 1/2 cup chopped celery
 1/2 cup chopped onion
 1/2 cup chopped carrots
 4 tablespoons all-purpose flour
 2 cups chicken broth
 2 cups whole milk
 1/2 cup heavy whipping cream
 12 chopped russet potatoes
 1 cup shredded sharp cheddar cheese
 1 tablespoon butter
 Sour cream, salt, pepper to taste

Directions

1. Fry bacon in a skillet and place on paper towel to drain.
2. Preserve 2 tablespoons of bacon grease in skillet.
3. Add celery, carrot, butter and onion to skillet and sauté for about 5 minutes or until they soften.
4. Add flour and stir.
5. Whisk in broth, heavy whipping cream and milk.
6. Add potatoes and bring to a boil.
7. Reduce heat and simmer for about 20 minutes or until potatoes are tender.
8. Add cheese and stir.
9. Season as desired with salt and pepper.
10. Add garnish as desired with crumbled bacon, sour cream, and extra cheddar



CF patient spotlight: Lora Moser

I live in Fort Worth, am married to Casey Moser, and I have two stepsons, Conner 11, and Jace 7. I'll be 38 in November and was diagnosed at 2 years of age, due to "failure to thrive". I love to go out dancing with my husband (its great exercise) and we are avid fans of all "Texas Red Dirt" country music. For our anniversary, he surprised me with a skydiving trip, something that I had mentioned to him in passing as a bucket list item, to do "before I die". I never dreamed he would make that dream come true, especially on our 1st Anniversary! I enjoy helping others, volunteering when I can, and increasing awareness about CF by simply telling "my story". It is all worth it if I feel like I can give one family hope that their little one can have a long, happy, and fulfilling life. I encourage everyone to talk about CF every chance they get especially those not directly affected by CF. The more awareness is increased, the more likely that awareness will turn directly into research funding. I hope that, throughout the course of my professional life, when someone mentions CF to a previous coworker of mine, they can say "Oh! I know about CF! I used to work with a fierce, brave, and friendly girl named Lora who has CF and she is still thriving!!!"

My "dream" in life is a bit nontraditional. But here it is: I dream of a cure for CF. I know there will be a cure. We are SOOOOO close. And for the record, I will be here to experience it!!

65 ROSES FOOD AND WINE EXTRAGANZA



65 Roses Wine and Food Extravaganza

October 14, 2015, 6:30 pm

Pavilion at Benbrook Stables

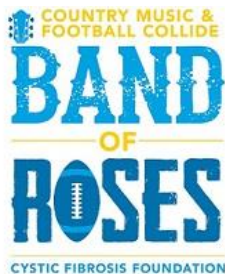
CFF (FORT WORTH)
CALENDAR OF EVENTS

Band of Roses

November 7, 2015

6:00 pm

Pop's Garage, Fort Worth, TX



FOR MORE INFORMATION

Executive Director: Amy Van Vranken
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 3840 Hulen Street, Suite 600
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FDA approves Orkambi

On July 2, 2015, the FDA approved the Orkambi drug for people with CF ages 12 and older who have two copies of the F508del mutation, representing 8,500 people or nearly one-third of the CF population in the United States. Nearly half of individuals with CF have two copies of this mutation and could eventually benefit from the therapy.

Orkambi was developed by Vertex Pharmaceuticals Inc. with significant clinical, scientific and funding support from the CF Foundation.

“We applaud the FDA for its swift approval of Orkambi,” said Robert J. Beall, president and CEO of the CF Foundation. “It is our hope that everyone who is prescribed this drug will have immediate access to it so they can begin to live longer, healthier lives.”

Beall continued: “We are proud of the important role that the Foundation played in the research and development of both ivacaftor and lumacaftor, including initiating the first efforts that led to the discovery and development of these small molecules.”

Orkambi improves lung function and significantly reduces the rate of pulmonary exacerbations, which can lead to frequent hospitalizations and accelerated lung disease. It is the second drug approved by the FDA that targets the underlying cause of CF. Ivacaftor (as a single therapy) was the first.

When Your Perfect Child Becomes a Teenager

When Betsy was diagnosed at 18 months, my job was to be consistent with her treatments until the day she would take these tasks on herself. We all know, that as our young children watch us, we are teaching by our example. So we were compliant.

And as the years passed, new treatments were added because of a positive culture, new diagnosis or research supporting new therapies. When my daughter was 6 years old, she was diagnosed with [CF-Related Diabetes \(CFRD\)](#), which came with a new set of therapies and additional monitoring. But again, we forged ahead and in the back of my mind, I heard that still, small voice, reminding me that things will get easier once she is able to do these treatments on her own.

Betsy is 15 years old now. While she's managed all of her oral medications independently since childhood, I began to transition her to manage her other therapies when she was 11. She is fully capable of doing all of her treatments on her own. This includes tending to her port and daily IV therapy, managing her breathing treatments and airway clearance, monitoring her diabetes with insulin, setting up her feeding bag every night and taking the countless oral medications she needs daily. This is what I've been waiting for! She's a smart, funny, athletic kid with countless true friends. She's on the honor roll and excels in sports. What I did not count on, is her teen rebellion.

While at a Parent Teacher Organization meeting, I was biting the inside of my cheek and pinching my upper arm as I listened to other parents complain about their teens turning assignments in late, not cleaning their rooms, or not keeping track of their athletic uniforms. I wanted to scream. What I wouldn't do for Betsy to rebel like that! Instead, my child, who has always been so well versed in her treatments (I recall her calling out a nurse about improper dosing of heparin when she was 3 years old) was not just skipping treatments, she was actually resisting them.

And she's mad. I don't blame her. CF is miserable. This makes perfect sense. The harder I push, the more she resists.

I read the blogs and stories parents write about their compliant CF kids, I hear CF adults speak about never missing a treatment or medication, and despite my best efforts, I am fighting a battle I never imagined with Betsy. If I've learned nothing else, it's to wave the white flag before I need it. For me, that meant getting the support of Betsy's team of clinicians

I am fortunate that Betsy is part of a comprehensive care team. The same doctor who talked to me 14 years ago was ready, willing and able to step in. Her team was eager to support her. They've seen this before and have the experience and tools to work with her. By meeting her anger with compassion, her resistance with compromise and her excuses with gentle explanations, we are turning a corner.

They've taken much of the weight off of my shoulders. They send Betsy emails encouraging her. They've also reassured me that this is not uncommon and that it's not my fault.

I'll never forget what my 3-year-old said after Betsy was diagnosed. Her world was turned upside down. She was forced to sit and watch as Betsy did her treatments and I beat on her little body as part of her therapy. She said, "Mama, I'll take some of Betsy's roses, but I don't want all 65 of them." I totally get that.

Fitting the demands of CF therapies into any schedule is challenging. As children and adolescents, most patients are able to somehow juggle this with their parents' support. But when that responsibility shifts to patients who are also faced with many other new challenges, it can become an overwhelming burden. High school, sports, friends and classes are the priority now for Betsy. Finding the support needed to help manage this complicated transition is critical to her health. The easy thing would be to do nothing and hope that she finds her way. Asking for help is hard. But being in the foxhole alone is even harder.

-CFF Community Blog written by CF parent, Mary Sullivan



Teenagers rebel. That's what they do. What I've learned is that anger and rebellion go hand in hand.

Cook Children's Staff Bios:



Anunya Hiranrattana, MD

Dr. H is originally from Thailand where she received her medical training. She completed her Pulmonology Fellowship at the University of Arizona in Tucson. In her spare time, she enjoys cooking and hiking. She is also having fun getting to know Ft. Worth. Dr. H. said she would be happy to answer anyone's questions about Thailand!



Juliann Gilmore, RN (Dr. H's nurse)

I grew up in Midlothian, however, soon, I will be moving into a house in Haslet. I went to nursing school at Southwest Adventist University and graduated in 2012. Since graduating I have worked at CCMC on the TCU/RCU unit and then was a middle school nurse before returning to work at Cook Children's in the Pulmonary Clinic. I have an 8 year old daughter and I'm excited to be gaining a step son in October when I get married. I am an extreme lover of Mexican food as well as scrapbooking, working in the yard, redoing furniture, and going camping.



Elisa Rowsell, CCLS

I grew up in Richmond, Virginia and went to Virginia Tech (go hokies!) where I studied Human Development. I recently completed my child life internship at The Children's Hospital of Philadelphia, and am excited about being in Texas near my family who relocated to the DFW area after I graduated high school. Outside of work, I enjoy spending time with friends and family and being active. One of my favorite places to be is at the lake with my family wakeboarding. I am thrilled to be a part of the Cook Children's pulmonary team and love being a child life specialist and being able to help kids realize that they can do things they never thought they could. ☺

Get the Word Out! CF Adult and Family Advisors Group

The CF Foundation is still recruiting for volunteers to provide input and feedback on a variety of projects and topic areas.

If you know a person within the CF community who may be interested in providing his or her unique perspective about CF care, research and quality of life, send them this application link: afasignup.cff.org.

The members of the Adult and Family Advisors Group (AFA) have been a great source for feedback and knowledge on a variety of topics. We encourage you to utilize the AFA as a resource when you need input from the experts who are directly affected by CF and to spread the word to others who may be able to use this group.

For information about this recruitment process or the projects and topic areas we are recruiting for, contact Danielle Lowe or Kelsey Fredkin at communityaffairs@cff.org.



The Flu and CF



In people with CF, the flu can lead to a severe lung infection, like pneumonia. If you have the flu, you may feel worse than you do with a typical lung infection or pulmonary exacerbation. Flu symptoms include:

- Body aches and headaches, Fatigue, Fever and chills, Increased cough, Sore throat

Contact your CF care center or doctor's office as soon as you feel flu-like symptoms. Antiviral medications used to treat people for the flu are most effective if taken within 24 hours of the start of symptoms. These drugs may help lessen your symptoms or how long you are ill.

How It Spreads

Like many germs, the flu virus can spread by direct and indirect contact and through the air. To reduce the risk of getting and spreading the flu, it is important for you and everyone around you to follow infection prevention and control practices like hand washing and getting vaccinated.

Reducing the Risk: the Flu Shot

The flu vaccine or “flu shot” can reduce the risk of getting the flu by helping the body fight off or increase its immunity to the flu virus.

It is best to get the flu shot early since it can take around two weeks after vaccination for the body to build up its immunity to protect itself against the flu virus. The best time to get the flu shot is in September through October, but getting vaccinated in December or January is still helpful as flu season can last until spring.

It is important to get the flu shot every year, since flu viruses are always changing. The flu vaccine cannot prevent all types of the flu virus, but it remains the best way to reduce the risk of getting the flu viruses that are most likely to make you sick in the current flu season.

People with CF can usually get their flu shot at a CF Foundation-accredited care center and through primary care providers. Talk with your CF care center to find out whether it has the vaccine available.

The flu shot does not give you the flu because the viruses in the flu shot are killed (inactivated). The risk of the flu shot causing serious harm is very small. However, like any vaccine, you could have mild side effects, which may include:

- Soreness or mild aches, Redness or swelling where the shot was given, A low-grade fever

If these problems happen, they will begin shortly after the shot was given and usually last one to two days. However, if you are not feeling better or start to feel worse, call your doctor.

If you do get the flu, you should try and stay home for at least 24 hours after your fever is gone. The fever should be gone without using a fever-reducing medicine, like acetaminophen (brand names include Tylenol®). A fever is defined as 100.4 degrees Fahrenheit or 38 degrees Celsius or higher. Children should not take aspirin if they have the flu or any viral infection.

Everyone Should Get the Flu Shot

Since the flu is highly contagious, encourage everyone around you, especially family members or people who live with you, to also get vaccinated to reduce the risk of getting and spreading the flu virus.

Children ages 6 months through 8 years may need two shots of the flu vaccine annually to fully protect them against the flu. Experts generally recommend four weeks between the two shots. However, ask your doctor if your child needs one or two flu shots and how far apart they should be given.



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

Pediatric CF Center Staff:

Center Physicians:

- James Cunningham, MD– Co-Center Director (Nurse: Stacy),
- Nancy Dambro, MD– Co-Center Director (Nurse: Karen & Danica),
- Maynard Dyson, MD (Nurse: Stacy),
- Sami Hadeed, MD (Nurse: Sharon),
- John Pfaff, MD (Nurse: Jessica),
- Karen Schultz, MD (Nurse: Paulette),
- Errin Newman, MD (Nurse: Lisa)
- Anunya Hiranrattana, MD (Nurse: Juliann)

Adult CF Center Staff:

Center Physicians:

- John Burk, MD– Adult Center Director,
- Jack Gilbey, MD
- Stuart McDonald, MD
- Randall Rosenblatt, MD
- Cyndy Roger, ACNP-BC (Nurse: Candace, adult nurse and newborn screening)

CF Coordinators:

- Janet Garbarz, Carrie Stradley 682-885-6299

Dietitians:

- Cara Dennert, Rachel Hamik, Esther Giezendanner 682-885-7496

Respiratory Therapists:

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

Child Life Specialist:

- Elise Rowsell, CCLS 682-885-4892

Social Services

- Aditi Prabhakar 682-885-3991

Research Nurse:

- Trudy Morris 682-885-1244

Pharmacist:

- Denise Pinal 682-885-2672

Cook Children's Medical Center and Cystic Fibrosis Center

Pulmonary Services:

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Phone: 682-885-6299, Fax: 682-885-1090, Email: www.cookchildrens.org

