COOK CHILDREN'S
CYSTIC FIBROSIS CENTER

FORT WORTH, TX.

COOK CHILDREN'S

FALL 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:

Healthcare Reform

Starting October 1st the health insurance marketplace will be open. This is a place where you can shop for insurance. Please take some time to look at this website if you or your family does not have insurance or are paying high costs for individual coverage. This website will help you determine what healthcare options you have, determine your tax credit (if you are purchasing insurance), and will have a navigator to help guide you.

-Please remember that all pre-existing condition clauses end January 2014, therefore anyone with CF will not be able to be discriminated against when purchasing insurance.

-If you qualify for a tax credit, it will be applied to your insurance premium directly. You will not have to wait for tax time to get your credit.

Ex: Individual income (1person) is $1301/mo which is 134% of Federal Poverty Level. This person will qualify for a tax credit of $212. If their premium is $252, the tax credit will be added, bringing their actual cost to $40. Tax credits will be for people earning up to 400% of Federal Poverty Level.

-A navigator can assist you in choosing a plan and submitting an application.

All insurance plans in this marketplace will include essential health benefits: Emergency services, Hospitalization, Laboratory services, Rehabilitative services, Prescription drug, Mental health, Substance abuse, Pediatric care, Maternity and newborn, Ambulatory services, Preventative and wellness.

https://www.healthcare.gov/index.html

For questions or assistance, please contact Social Worker, Amy Wilson, LCSW at 682-885-3991

504 Plans

Generally speaking, patients with CF will qualify to receive special provisions while at school under Section 504 of the Rehabilitation Act of 1973. You can make sure your child is covered under these provisions by contacting the school counselor or administration to ask for consideration. After you start with this process at school, the CF team will write a medical letter outlining the illness, treatments, and how these things will impact school. Some things outlined in this letter are taking enzymes before eating, allowing student to have snacks, allowing students to have frequent bathroom breaks, etc.

Please contact Social Worker, Amy Wilson, LCSW at 682-885-3991 for more information.

Helpful Information for Teachers on CF at School

As the school season starts, make sure CF patients and their parents know what information is available to help teachers, coaches and school staff learn more about CF. Multiple resources are available at www.cff.org/LivingWithCF/AtSchool, including:

- **Infection Prevention and Control Recommendations: More Than One Person with CF in the Same School: Provides recommendations to minimize the spread of germs between people with CF attending the same school.**
- **A Teacher's Guide to CF: Features questions and answers for teachers who may have a student with CF in their classroom.**
- **Letter for Schools about CF: Offers a template letter that parents, families and**

CF and Massage

The Benefits of Massage for Cystic Fibrosis

By: Amy Wynn, LMT, Good Juju Massage & Bodywork

Really? Massage? Yes, really! Massage can help manage Cystic Fibrosis. Don't think of massage as a dimly lit room in a luxury spa that you have to pay through the nose for. Think of massage as a tool to help you reduce your child's -and your- anxiety, muscle tightness, improve circulation, breathing, and general sense of well being.

Massage, simply put, is the manual manipulation of muscle and tissue. Cystic Fibrosis comes with issues like chronic coughing, pain, long daily treatments, and other movements that cause repeated constriction of the same muscles. It can be very easy for those muscles to become chronically constricted- meaning even when the activity that flexes the muscle is over, the muscle doesn't relax, but stays flexed or tense, leading to discomfort and other problems. Many CF patients will begin to see a forward hunch in their shoulders after years of constant coughing. Massage can help to release that tension and maintain healthy, balanced muscle tone. Healthy, balanced, and relaxed muscles make the work of breathing an easier task, and massage has even indicated improved pulmonary function for individuals with CF.

Massage also stretches and relaxes veins and capillaries, improving circulation. Some toxins, or waste, are naturally expelled through our lymphatic system, and massage stimulates and assists in this process as well. Improved muscle strength and sleep quality are also effects of massage. Some techniques also include positioning the body and working in such a way that they help mucous to drain for the respiratory tract- very much in the same manner as performing manual CPT.

Children with CF who receive regular massage from parents or caregivers show improvements in mood and decreased anxiety, but more surprisingly, so do the parents administering the massage.

Since children tend to have a harder time laying still for long periods of time, shorter durations - 10 to 20 minutes, are more appropriate for pediatric massage. Children also have more responsive muscles than adults, and therefore need less pressure to release their muscles.

While there are many kinds of massage, studies do not show that any one is more effective than another for producing positive effects for those with CF. If you're interested in trying massage on your child, there are many resources for infant and pediatric massage- as easily as you can Google or search YouTube, you will find techniques to start you on your way. Just like your doctors and nurses, our first rule as LMT's is to do no harm, so use good sense and if you see something that doesn't look right to you, don't try it! You may also be able to contact a local massage therapist who can massage your child and may be willing to teach you some tactics for home use.

To find a Licensed Massage Therapist in your area, or to find a therapist who specializes in medical or pediatric massage, go to www.amtamassage.com for the listing by the American Massage Therapy Association.

For more information on studies of the effects of massage on Cystic Fibrosis, go to:

http://www.guideline.gov/content.aspx?id=14578

http://www.ncbi.nlm.nih.gov/pubmed/10361400

http://umm.edu/health/medical/altmed/treatment/massage

Cook CF Patient Spotlight!

Jared Eaken

1. Fun Facts:

Loves the Texas Rangers
Nascar Fan – Go Jimmie Johnson!
Favorite Food – Mac N Cheese (Especially from Outback Steakhouse)
Downtime – Xbox, Legos, Playing Baseball
Pet – His cat Oreo
He is the proud big brother to his sister Lilly

2. About his Diagnosis

His symptoms were primarily digestive. We began having concerns around age 18 months and kept playing with his diet to see if symptoms would improve. Shortly after his 3rd birthday, he had a rectal prolapse. Within a week he was diagnosed with CF by sweat test. Several weeks later his mutations were identified through DNA testing.

3. Special Spaces

Jared received a wonderful gift from Special Spaces of Fort Worth this past August. They did an extreme makeover of his bedroom in the theme of the Texas Rangers. In addition to the awesome-looking de-

sign, they gave him some really neat "stuff". His favorite items (and it's hard to narrow it down) were the autographed Beltre jersey and the official stadium seats. He also enjoyed a private tour of Ranger stadium and time in the Kid Zone with just him and his sister.

4. Balancing Life with CF

This November will be 10 years since his diagnosis. It's been quite a journey! His daily routine is way more extensive than it was back then. Approaching the teen years, we can see more resistance creeping in, BUT most of it is still routine enough that he doesn't even think about it. We have an amazing support system of family and friends to have our backs during the rough times like hospitalizations, surgical procedures, and home IVs. Jared's CF is a big part of his life, but it is not what his life is about. It's about so much more…. "When can I see my cousins again?" "Can we rent a movie or go see one?" "Can I spend the night at my Grandparents house?" "Will the Rangers make the playoffs?" "I can't believe that Jimmie lost the points lead!" "Is it too cold to swim????" "Can we start planning my birthday party?" "Oreo is messing up my Legos!" And my personal favorite: "How many days until summer?"

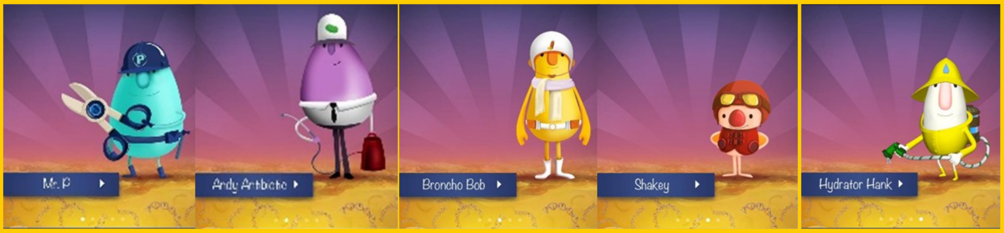
Muckbusters Game App

Ever wish there was a fun, interactive way to educate your children about cystic fibrosis? Muckbusters does just that! Muckbusters utilizes a variety of “characters” that represent different elements of CF care to help defeat mucus, bacteria, and viruses. A few of the characters include:

Mr. P represents Pulmozyme and his job is to cut up the DNA in the mucus and ultimately clear away mucus. Andy Antibiotic exterminates bacteria and helps to prevent and treat infections. Broncho Bob opens up blocked airways. Lastly, Shakey does lots of jobs at once, pushing DNA, broken up DNA, and bacteria out of the way.

The game can be a little tricky to get the hang of at first but this encourages players to read more about each of the “characters.” This in turn can provide a fun opportunity for players to learn more about cystic fibrosis. Be warned that comparable to many games available for smart phones these days, Muckbusters can be very addicting!

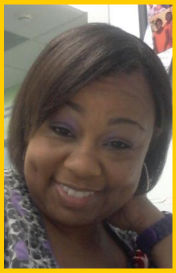
An additional component to the game includes a daily tracking form for players with CF to complete if desired. Every time players complete the daily tracker they can receive a bonus. However, the best two parts to this game are the following, it is completely FREE and it truly emphasizes how important it is to rid the body of mucus! Try utilizing this game as a new way to talk to your children about the importance and purpose of their CF care. Let us know what you and your children think of this game at your next clinic visit.



Spotlight on our MA's!

Kisha Wright- Medical Assistant

My name is Kisha Wright, I am a Medical Assistant in the Pulmonary Clinic. I am a local lady who was born and raised here in Fort Worth, Texas. I can always be found somewhere smiling in the clinic. I love children and I have been here @ Cook's for 6 years! Woohoo! I am currently attending the University of Phoenix to pursue a Bachelors of Science degree in Healthcare Administration with a concentration in management.

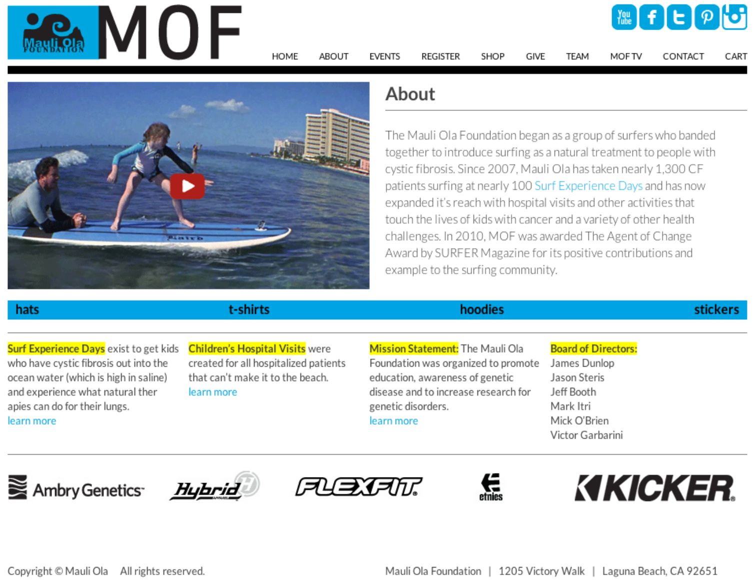


Marquietta Jones- Medical Assistant

Born and raised in Fort Worth, Texas. I have worked at Cook Children's Medical Center for 9 year, and in the Pulmonary Clinic for 8 years as a Medical Assistant. I am a graduate of the University of Texas at Arlington, and will be pursuing a career in nursing. I love working with the children, and love to see them smile!

Breath of Life Program

http://www.mauliola.org/



About

The Mauli Ola Foundation began as a group of surfers who banded together to introduce surfing as a natural treatment to people with cystic fibrosis. Since 2007, Mauli Ola has taken nearly 1,300 CF patients surfing at nearly 100 Surf Experience Days and has now expanded it's reach with hospital visits and other activities that touch the lives of kids with cancer and a variety of other health challenges. In 2010, MOF was awarded The Agent of Change Award by SURFER Magazine for its positive contributions and example to the surfing community.

Surf Experience Days exist to get kids who have cystic fibrosis out into the ocean water (which is high in saline) and experience what natural therapies can do for their lungs.
learn more

Children's Hospital Visits were created for all hospitalized patients that can't make it to the beach.
learn more

Mission Statement: The Mauli Ola Foundation was organized to promote education, awareness of genetic disease and to increase research for genetic disorders.
learn more

Board of Directors:
James Dunlop
Jason Steris
Jeff Booth
Mark Itri
Mick O'Brien
Victor Garbarini

Copyright © Mauli Ola All rights reserved.

Mauli Ola Foundation | 1205 Victory Walk | Laguna Beach, CA 92651

Got New CF Vitamins?

By: Cristina Puga, RD, CSP, LD

CF Dietitian

If you have received new vitamins in the mail, from the CF CareForward program, don't be alarmed! New options are now available for CF vitamins. Within the past couple of months, two new vitamins have been released.

1. ***Complete Formulation Multivitamin***

Manufacturer: M.V.W. Nutritionals, LLC

Forms: Softgels and chewable (liquid coming soon)

Website: http://mvwnutritionals.com

Note: This vitamin is currently available through the CF CareForward program (Creon assistance program) and through the Cystic Fibrosis Pharmacy. Your pharmacy may be able to order through the manufacturer soon.

2. ***ChoiceFul Vitamins***

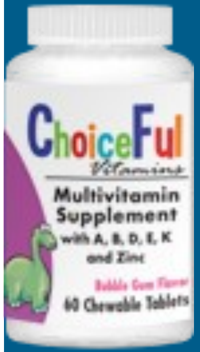
Manufacturer: National Vitamin Company

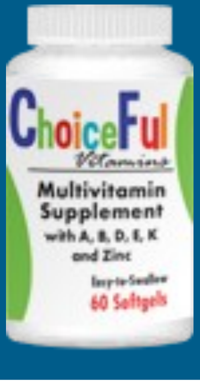
Forms: Softgels and chewable

Website: http://www.choicefulvitamins.com

Note: This vitamin is only available through their speciliaty pharmacies, FC Foundation Care or/and IVS solution. Information available on their website.

Before you make a switch to any new vitamins, please contact your CF dietitian to determine if it is an appropriate change. The recommendations provided to you, through the CF Dietitians, are based on individual vitamin lab values; not every CF patient needs the same type of vitamin. As a reminder, it is recommended that all vitamins be consumed with a meal and with enzymes (if needed).





Mark your Calendars!

The Cook Children's North America Cystic Fibrosis Conference Family Update will be :

November 18 from 7-8:30pm

Auditorium

This update will also be available as a webinar. Postcards and emails will be sent out to families with information for submitting questions and accessing the webinar.

Remember to Get Your Flu Shot!

Every year, people get influenza (the flu) in the fall and winter. That is why it is called "seasonal" flu. The flu shot this year will help protect against different strains of influenza, including the H1N1 flu strain. The best way to prevent the flu, including H1N1 flu, is to get vaccinated. The Centers for Disease Control and Prevention (CDC) recommends that all people ages 6 months and older get the flu vaccine or "flu shot." Based on the CDC's recommendations, the Foundation urges everyone with CF and those who live in the same household to:

- Get the seasonal flu vaccine as soon as possible.
- Follow your local care center's or doctor's recommendations on getting vaccinated for seasonal flu.

Flu shots are important to help avoid the flu

Children ages 6 months through 8 years may need to get 2 doses of the seasonal flu vaccine.

Appointment Reminders!

Did you know you can sign up for text message reminders for your appointments at Cook Children's?

- Log on to your patient portal account at **https://www.cookchildrens.org/ForPatientsFamilies/Pages/mycookchildrens.aspx**
- Under my profile, click on Contact Preferences and select text message under appointment reminders and then click Save.

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: Kristi, 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	682-885-3991

Cook's Corner: Recipe for Success

Shepherd's Pie

Ingredients

1 c. high-calorie mashed potatoes

1/3 c. sliced mushrooms

8 oz. ground beef

1/3 c. onion, diced

2 tsp. Worcestershire sauce

2 cloves of garlic, minced

1 tbsp. flour

½ c. beef gravy

1 carrot, shredded

1/4 tsp. marjoram

Directions

1. Sauté mushrooms, garlic, and onions until tender, approximately 7 minutes. Transfer mixture to bowl.

2. Cook beef until brown in skillet over medium heat, approximately 8 minutes. Add flour and stir for 2 minutes. Add mushrooms, onion, garlic, gravy, carrot, Worcestershire, and marjoram. Simmer for 4 minutes, stirring occasionally.

3. Spoon beef mixture into a small baking dish or two oven-safe bowls. Spoon mashed potatoes over top of beef mixture. Bake at 350 degrees until heated through and golden brown, approximately 25 minutes.

Nutritional analysis (per serving): 922 calories 34 g protein 72 g fat 931 mg sodium 111 mg calcium