Cook Children's Cystic Fibrosis Newsletter

SPRING 2015

IN THIS ISSUE

Tips for a CF Vacation

By: www.cff.org

What's the best way to have a good trip? Be prepared. Start with this checklist of things to do three to six months before you travel.

- Check in with your CF center before booking your trip to make sure you get a travel note and to assess your medical status. If you are not feeling well, you may need to be treated prior to your trip. You also should discuss a plan for treatments if you become sick and any impact time-zone differences may have on timed medications.
- Check on immunizations required for international travel.
- Make lists of medication and supplies you will need on your trip ahead of time. (Check and recheck this list!)
- Make sure you request a refrigerator at the place you will be staying for medications that need to be kept cold.
- Count all medications well ahead of your trip and get refills (order a month or so in advance if you use a mail-order pharmacy). You may need to talk with your insurance provider for refills needed prior to your trip; some will provide a "vacation allowance."

What to Pack

- Make a list of emergency contacts in case you become sick or have problems with such things as your luggage.
- Bring a list of doctors who specialize in CF so you can get appropriate care if needed. Check the CF Foundation's website (for national travel) and Cystic Fibrosis Worldwide (for international travel) for locations of CF centers.
- Pack alcohol-based hand sanitizer with you for good hand hygiene.

Make-A-Wish Foundation wants to grant more wishes!!

Make-A-Wish® grants the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy. It's a mission, and a privilege the organization takes very seriously. Make-A-Wish grants a wish every 38 minutes – more than 14,000 just last year! The wish experience allows kids battling life-threatening conditions to experience something beyond their medical conditions. It is a time when optimism and renewal overshadow their illness and treatment. And, most children with Cystic Fibrosis are eligible to receive a life-changing wish!

Make-A-Wish has carefully researched and reviewed the guidance around our eligibility criteria for Cystic Fibrosis. With the input and support of leading pulmonologists and Make-A-Wish medical advisors across the country, we determined that, effective Feb. 1, 2014, **all patients with Cystic Fibrosis, except for those rare circumstances when they are free of respiratory involvement**, will be eligible for a Make-A-Wish experience.

If you would be interested in pursuing a wish for your child and if he/she has not previously received a wish granted from us, or another wish-granting organization, please contact our local chapter, Make-A-Wish North Texas, at (888) 625-3294 or you can start the referral process online at md.wish.org.

Christy Livingstone

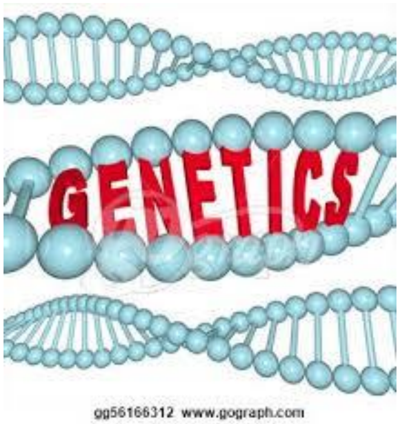
Medical Outreach Coordinator

Make-A-Wish® North Texas

GENETICS 101

Ambry Genetics recently premiered "Genetics 101: What is Exome Sequencing?" video

This video offers a patient-friendly, engaging overview of basics in genetics, which build upon each other, to explain how exome sequencing works. Although this is not a CF specific video, it provides a basic explanation of genetic mutations.



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

Cook's Corner: Recipe for Success

Vitamin C Booster Smoothie

This smoothie has been a great way to sneak in some extra calories and lots of veggies and fruits to boost our immune systems! The kids have no idea there is kale in there and that's fine with me!

Ingredients
1 cup frozen pineapple
1/2 cup orange juice
1 cup full fat vanilla yogurt
1 cup fresh, washed kale

Directions
1. Put all the ingredients into a blender and blend until completely mixed.

Serving Size

Serves: 1 serving
Calories per serving: 500
Fat: 7 g
Sodium: 105 mg
Protein: 8 g
Calcium: 326 mg

CF patient spotlight: Graeme Jaetzold

by: Jennifer Jaetzold, mother

Graeme is 4 years old! He has the sweetest, most gentle heart! He loves to play with anything and everything that involves construction trucks and dinosaurs. He also loves to ride his bike and scooter with his sister and brother. Graeme is so excited to start PreK next year. He loves to learn and color in his Transformer coloring books. Graeme was diagnosed with Cystic Fibrosis at 3 weeks of age via Newborn Screening. He has an older sister that also has CF.

We have been going to Cooks since 2008 as that was the time that Graeme's older sister was diagnosed. We love the entire team at Cooks. They truly listen to our concerns, discuss options for our children, and genuinely love our family. Our dream for Graeme is that he will always strive to be a God-fearing, loving, caring young boy with a warrior spirit, and that CF will never get in the way of his dreams and passions. ....And that he will always stay a mommy's boy ☺

CF CLIMB

CF CLIMB

CF CLIMB FOR LIFE 2015

This CF event is now open for registration!

August 15, 2015

Check in: 8:00am, Start time : 9:00am

Number of Steps: 20 floors

Location: Pier 1 Building, downtown Fort Worth

CFF (FORT WORTH) CALENDAR OF EVENTS

Great Strides 2015

Change of Location

May 17, 2015

The Ft. Worth/Arlington CF Great Strides event has changed locations..

Quik Trip Park, Grand Prairie, TX.

FOR MORE INFORMATION

Executive Director: Amy Van Vranken
Northeast Texas Chapter-Fort Worth
3840 Hulen Street, Suite 600
Fort Worth, TX 76107
T: 817-249-7744
F: 817-249-7780
E: fortworth-ne-texas@cff.org

Great Strides 2015

Great Strides 2015 may be in the books, but that doesn't mean you have to stop fundraising! Keep up the great work and let's help achieve the Great Strides FW chapter goal together!

Friends and families came together from all across North Texas on May 17 for one cause... to raise vital funds for cystic fibrosis. It was rainy and wet, but that didn't stop all the teams from celebrating their fundraising efforts!

Passion

A Passion Fundraising event is created when a Great Strides participant is inspired by their favorite hobby or pastime to develop a unique fundraising event or opportunity. Passion fundraising allows participants to elevate their Great Strides fundraising efforts by getting friends, family and community involved in a fun, exciting and personalized way.

What is an example of a Passion Fundraising event?

- Dinner
- Polar bear plunge
- Wine tasting event (age 21 over)
- 5k run
- Concert
- Zumba

New Passion Fundraising Online Tool

1. Customizable webpage available for registered Great Strides participants
2. Organizers can promote event, register attendees, sell tickets, recognize corporate donor and use social media.
3. Look for your Passion Fundraising button as seen on your Great Strides event page to create your own event today!

Events that cannot be hosted on our Passion Fundraising online toll

- Raffle/drawing/any kind of contest where luck is involved
- Auctions
- Selling any items where a portion of the proceeds goes to CFF
- A percentage of sales campaign
- An event that requires CFF's insurance

Support

Please call the customer service hotline at 1-855-407-3750, Monday through Friday from 8:30 am-5:30 pm ET for assistance with the Passion Fundraising online tool.

To host your fundraising event to benefit Great Strides, click below:

Passion

Fundraising

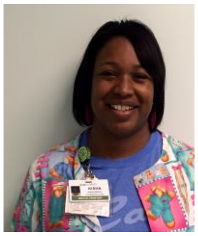
GREAT STRIDES

CYSTIC FIBROSIS FOUNDATION

Cook Children's Staff Bios:

Aditi Prabhakar, LMSW

My name is Aditi Prabhakar and I am the new Social Worker in the Pulmonary Clinic at Cook Children's. I was born and raised in the great state of Texas! I graduated with my undergraduate and graduate degrees from UT Arlington. In my free time, I love spending time with my family, traveling, and exploring new places. I am a huge animal lover and have two wonderful rescue dogs! I am very excited to be here at Cook Children's in the Pulmonary Clinic!



Kisha Wright MA

I was born and raised here in Fort Worth, Texas. I have been at Cook Children's for 8 years as a Medical Assistant in the Pulmonary clinic. I love my pulmonary family, and I have a beautiful family of my own, three daughters and one son. I am in the process of obtaining my bachelor's degree in Health Care Administration with a concentration in management. I love to help people in any way possible. In my spare time I love to cook and sing, sometimes at the same time! LOL

CF Goes to School

Cook Children's CF clinic will be hosting a school forum for parents regarding all aspects of school. Do you have questions about packing school lunches,504 plans, tips/tricks for your child, school accommodations? If you have a child entering preschool or even high school… this is for you! A parent panel, dietitian, school nurse, and CF staff will answer questions! Come and pick up free resources too! July 14, 2015, 7:00 pm in Hochberger Auditorium, lower level near Camelot Court

Life hack: The Pillbox

by: Gunnar Esiason

The first life hack that immediately comes to mind is the "pillbox." I'll admit, this is a pretty common thing, but I was without it for a while. A friend of mine with CF introduced me to the pillbox when I was in high school. You can find them anywhere on the Internet. I would imagine a pharmacy has them too. I know some people love to use the "weekly" pillbox, which is designed to help people to remember when to take their meds throughout the whole week. Personally, I prefer the daily pillbox. I've built it into my daily routine to put all of my necessary meds in the box at the beginning of the day. The particular one that I use has a large compartment for enzymes, then smaller compartments for any antibiotics, antacids or vitamins that I may need on a given day. Plus there's room for *auxiliary* pills. Let's be honest, you're someone with CF, you never know when you may need ibuprofen or something like that. The bottom line is that the pillbox makes all necessary meds available, and most importantly, the pillbox makes it very easy to remember to take those pills. If I ever want a candy bar, I'm in luck because I have my enzymes on me. I always make sure I have the box with me when I leave the house. In fact, it's gotten to the point where my friends are shocked if I ever don't have it with me.

COMMUNITY & COLLABORATION
2015 VOLUNTEER LEADERSHIP CONFERENCE
CYSTIC FIBROSIS FOUNDATION

On the heels of exciting progress in the fight against CF, more than 500 of the Cystic Fibrosis Foundation's most dedicated volunteers, chapter staff and corporate supporters came together at the 12th annual CF Volunteer Leadership Conference, and hundreds more watched via live stream March 20-21.

Two families from the Northeast Texas, Fort Worth Cystic Fibrosis Chapter were able to attend the conference. It was an extraordinary two days, reviewing the tremendous progress made in the search for a cure and the amazing opportunities we have to move forward in our ultimate goal.

Volunteers discussed ways the CF community can work together to sustain progress in the research and care while helping improve the lives of people with the disease.

The conference speakers encourage us to collaborate with other to advance our shared mission by celebrating our passions, networking in our communities, and telling our stories. This can be achieved by:

Goal 1: Celebrate your passion and enhance our fundraising efforts

- Use your passion to create an event on our new passion fundraising website to help you exceed your Great Strides fundraising goal
- Use your passion to engage friends and family in our individual giving efforts
- Use your passion to create awareness for all your chapter fundraising events

Goal 2: Network to bring new people to our community

- Share your fundraising ideas and volunteer experiences and ask other to join our efforts
- Share out mission and remind your family, friends, and business acquaintances that our goal is to find a cure for CF and provide all people with the disease the opportunity to live full, productive lives.
- Share your goals for the future and how you will get there through collaboration with others in the CF community

Goal 3: Tell your story to educate the ways in which we serve the CF community

- Educate the community CF services, advocacy efforts and care center in your local area
- Let your friends and family know your "Why I Stride" story
- Integrate social media into your communications and fundraising plan

"Thanks to the hard work, dedication and steadfast support of our loyal and passionate volunteers, there is more hope in the CF community than ever before," Beall said. "Our volunteers know that by coming together with local communities and collaborating with others, we can end this disease."

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 & Danicka),
- Maynard Dyson, MD (Nurse: Stacy),
- Sami Hadeed, MD (Nurse: Sharon),
- John Pfaff, MD (Nurse: Jessica),
- Karen Schultz, MD (Nurse: Paulette),
- Erinn Newman, MD (Nurse: Lisa)

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: Laura, 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:

- Heather and Brittany 682-885-4181

Social Services

- Aditi Prabhakar 682-885-3991

Research Nurse:

- Trudy Morris 682-885-1244

Pharmacist:

- Denise Pinal 682-885-2672

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Phone: 682-885-6299, Fax: 682-885-1090

Email: www.cookchildrens.org