

# Cook Children's Cystic Fibrosis Newsletter



SUMMER 2016

## Hydration and Cystic Fibrosis

When young athletes with CF perspire during exercise, the sweat their bodies produce has a higher salt concentration. As a result, athletes with CF:

- Lose more sodium:** When an athlete with CF finishes sports or recreational activity, they have lost more sodium from their body than the average athlete;
- Feel less thirsty:** The thirst sensation in athletes with CF does not turn on as quickly as for other athletes, or may not be triggered at all. Experts speculate that this may be due to the excess sodium loss through sweat, but such a connection has not yet been established definitively through research. [Note: As far as we know, no new research has been conducted in active youth with CF looking into hydration concerns and solutions since 1999];
- Voluntarily drink less:** Research shows that youth with CF drink 50% less than healthy counterparts when given water;



- Are more prone to dehydration:** Youth with CF tend to become dehydrated even when given a typical flavored sports drink containing carbohydrate and sodium; and
- Don't find high sodium sports drinks "palatable."** Youth with CF, when given a high sodium sports drink, drink more than when given a sports drink containing regular amounts of sodium, but don't like the taste.

### Hydration Tips for CF Youth

- Flavored, high sodium sports drinks.** Give CF athletes commercially available, flavored

#### IN THIS ISSUE

- Hydration and CF
- Vacationing with CF
- Parent CF Hacks
- Recipe for Success
- CF patient spotlight
- CFF-FW upcoming event
- Orkambi
- Camp Kindred
- Staff Bios
- Cook Children's CF Clinic Webpage
- CF Scholarships
- Staff

sports drinks containing carbohydrates and higher levels of sodium

- Add salt to regular sports drinks.** As an alternative, add  $\frac{1}{4}$  teaspoon of salt to one quart of a regular sport drink (although, as noted above, the athlete may not like the taste).
- Be careful about pushing consumption beyond thirst.** Don't necessarily push a child with CF to drink beyond thirst, but be aware of estimated fluid losses during a practice/game and replace as needed instead.



# Vacationing With CF

Staying healthy with cystic fibrosis (CF) is a challenge no matter what, but it can be even more difficult to stay on track when distracted by both the excitement and stress of traveling.

As you embark on your 2016 vacation destination, it's important to remember to keep both yours and your family's nutritional needs in check. Here are some quick tips that our family found essential while our daughter with CF was growing up, and that she now incorporates into her own family's travel plans:

## Plan ahead

Anticipate situations where proper nutrition may not be available and plan ahead to bring meals and snacks that can be eaten on-the-go, if needed. While away from your everyday environment, it may be tempting to forget to keep track of eating schedules and proper meal planning. Avoid potential complications and slip-ups by being mindful of this before you pack your bags.

## Stock up smartly

One of the best ways you can look out for your family's health is to shop with a purpose prior to your departure. Stock up on high-caloric, easily-accessible snacks like trail mix, dried fruit, granola bars, cheese and cracker packs, and pretzels. Keep perishable items, such as cheese sticks, hummus, cottage cheese, and yogurt, cool with an insulated lunch bag or cooler.

## Bring your vitamins

Another way to avoid potential nutrition-related hiccups in your vacation schedule is to incorporate vitamins A, B, C, D, E, and K into your diet. Vitamins are always important for people living with CF, but supplements such as vitamin A and E are especially needed while travelling because they can help to fight infections and boost the body's ability to protect itself when sick.

Planning ahead and packing meals in advance of your vacation may seem like a bit of a hassle initially, but a little extra effort now could help ensure that you will be able to stay healthy and make the most of this time-off with your family.

## Parent CF Hacks



Do you have a tool or a solution that helps make you or child's CF life easier? We want to hear about your Parent CF Hack!

A mother of two children with CF was having a difficult time managing and organizing multiple systems during nebulizer treatments. "Two vests, two Hill Rom machines, two nebulizer compressors. There were hoses everywhere!" the CF mother states. She mentions that her family was exploring the vast and exciting world of Ikea one weekend. The Ikea Raskog cart was then discovered. "I knew as soon as I saw the Rasgkog cart- this storage unit would be the perfect solution for organizing all our CF equipment in the treatment room." She excitedly stated that each CF child has his/her own cart, and the Hill Rom machine sits on top, vest in the middle, and nebulizer compressor on the bottom. The cart comes in three different colors: turquoise, beige, and black and retails for \$29.99 at your local Ikea store.



For other great CF high-calorie  
recipes check out:  
[www.chef4cf.com](http://www.chef4cf.com)

## Cook's Corner: Recipe for Success

### Cheesy Hash Brown Casserole

#### Ingredients

- 1 package shredded frozen hash browns
- 1 stick butter
- 8-oz package shredded cheddar cheese
- 1 can of cream of chicken soup
- 8 oz sour cream
- 1 package French fried onions

#### Directions

1. Preheat oven to 375 degrees.
2. Spread frozen hash browns in a 9x13 pan.
3. Melt butter in a microwave safe bowl.
4. Mix melted butter, cream of chicken soup, sour cream, and cheese.
5. Spread mixture on top of hash browns.
6. Bake for 30 minutes.
7. Sprinkle French fried onions over the top and bake an additional 10 minutes or until bubbly.

#### Serving Size

Serves: 12 servings  
Calories per serving: 273  
Fat: 23 g  
Sodium: 336 mg  
Protein: 7 g  
Calcium: 170 mg



## CF patient spotlight: Layla Jean Waller



Layla Jean is 5 years old going on 13. She loves life and makes everyone's lives she is around more joyful singing and dancing her way through the day. Layla loves anything with a princess on it but also loves to go fishing with her brother at Lake Grapevine or up in Arkansas with her cousins. Layla was diagnosed with CF while I was pregnant through an amniocentesis done by our amazing perinatologist, Dr. Graham at Baylor Grapevine. Once the diagnosis was made I said that I would give myself a day to be angry, sad and feel all of the emotions but then after that day it was going to be JOY and only Joy through our walk with Cystic Fibrosis. That brings us to today...we've had some ups and downs with hospital visits and figuring everything out but all the while we remain filled with joy and confident in our extraordinary team at Cook Children's and Southlake Family Medicine. We WILL find a cure and will all celebrate together. Until then I am going to take Layla's lead and dance my way through the ups and downs of life with Cystic Fibrosis!

## UPCOMING CF (FORT WORTH) EVENTS

## CARA YOUNG FISH FOR LIFE TOURNAMENT

Sunday, September 18, 2016

The anglers will be fishing Lake Grapevine, with the weigh-in being held at Cabela's Fort Worth store location.

Scott Gordon will be the tournament director this year. Entry fee will be \$150.00 per team, big bass included.

Please visit Scott's website, <http://gordonoutdoors.squarespace.com> for a complete listing of the rules.

The free kids fishing tournament will also be held at Cabela's the same day from 9:00 a.m. until 2:00 p.m. for kids 12 and under. Hourly weigh-in and prizes for the big fish each hour. A \$50.00 Cabela's gift card will be awarded for the biggest fish of the day.

We also are currently selling tickets for a chance to win a Big Green Egg. Tickets are \$5.00 each, or five for \$20.00. This will be given away on tournament day. Huge THANKS to Monte Coon for making this happen again this year!

Our banquet and silent auction this year is scheduled for Saturday, October 29th at the Fort Worth Botanic Gardens.



## FDA Accepts Priority Review for New Drug Application of Orkambi, 6-11 age group

On May 31, 2016, Vertex Pharmaceuticals announced that the U.S. Food and Drug Administration (FDA) has accepted for review a supplemental New Drug Application (sNDA) for the use of ORKAMBI® (lumacaftor/ivacaftor) in people with cystic fibrosis (CF) ages 6 to 11 who have two copies of the F508del mutation. The FDA granted Vertex's request for Priority Review of this sNDA, and a target review date of September 30, 2016 .

Approximately 2,400 children ages 6 to 11 have two copies of the F508del mutation in the U.S.-

Orkambi improves lung function and significantly reduces the rate of pulmonary exacerbations, which can lead to frequent hospitalizations and accelerated lung disease. It is currently available for ages 12 years and older. Orkambi is the second drug approved by the FDA that targets the underlying cause of CF. Ivacaftor (as a single therapy) was the first.

# Cook Children's Camp Kindred Sibling Camp

Cystic fibrosis can affect individual patients in a variety of ways but it is no secret that every member of the family is greatly impacted. In April, our CF center will join the CF center at Dell Children's to offer a special 2 night weekend camp for children that have an immediate family member with cystic fibrosis. Camp Kindred is held at Camp John Marc in Meridian, TX. Through Cook Children's 'Camp for Kids' program we are happy to announce that the weekend was completely free of charge! We provided transportation from the hospital to camp, all meals, activities, and trained counselors for the weekend. Activities at Camp John Marc are designed to build confidence in children and provide an opportunity to have new life experiences. These activities include: ropes course, star gazing, cooking, arts and crafts, fishing, archery, sports, and nature activities.

Part of the focus of the weekend was to provide a safe place for children to express and share their own personal experiences about having a family member with CF. The focus will be on the sibling or son/daughter, and not the medical experience of the family member with CF. Most of the weekend was spent having fun, playing outside, and just being kids, but campers did have the option to attend a short session specifically focused on emotional expression. Please note that the camp was for those related to someone with CF, not CF patients themselves. The mission of Camp Kindred is for siblings of children with CF and children of adults with CF served by Cook Children's and Dell Children's. Children ages 7 (by camp start date) and older are welcome to attend.

Sydney Powell was one of the campers that attended Camp Kindred, and we asked her a few questions about her first experience at camp.



**“Sydney Powell, 8 years, is the best helper when it comes to caring for her 6 year old sister Aubrey, who has CF.”**

1. Why did you want to go to Camp Kindred?  
-I thought it would be fun and to meet other kids that know about CF.
2. What is your connection to the Camp?  
-My sister, Aubrey, has CF
3. What was your favorite part about the Camp?  
- Activities like star gazing and making s'mores
4. Did you learn anything at camp?  
- I learned that it's ok to have a sibling with a disease.
5. Would you like to go back next year?  
- Of course!

# Cook Children's Staff Bios:



## Heather Urbanek, RN (Research Coordinator)

Heather is one of our Research Nurses who is very passionate about finding a cure for CF. She has been a research coordinator for about 9 years and came to Cook Children's about 3 years ago. Heather is a married mother of three : a german shepherd and two cats. She is a proud Aggie who enjoys reading, painting, and traveling in her spare time. Heather loves working at Cook Children's and serving our wonderful families.



## Courtney Wolff, BSN, RN (Research Nurse)

Courtney is our newest CF Research Nurse who joined us in April of this year. She graduated from Texas Woman's University Nursing School in 2010 and has since worked solely in pediatrics. For the first 3 years of her career, Courtney served as an elementary school nurse right here in Fort Worth ISD. She made the move to Cook's in Dec 2013 to be a Diabetes Educator. When not working, Courtney spends most days running around with her Golden Retriever, Booger, or cooking up yummy vegan dishes. She enjoys reading, playing tennis, running half marathons, and going to Ranger games. As a native of Fort Worth, Courtney has long revered the Cook's legacy and is more than proud to be a part of this organization.

## Heather Leach, Research Associate



Heather was born and raised in Fort Worth where she still lives with her husband, 1 ½ year old little boy, and 10 year old Yorkie. She joined Cook Children's in June 2012 working in Pulmonary as a Medical Receptionist then came to the research team in March 2015 as a Research Associate. In her spare time she loves playing with her son and going on new adventures with her little family. Heather really enjoys working with the Research team in helping to find a cure for Cystic Fibrosis.

## Cook Children's CF Center Webpage

Have you had a chance to visit the Cook Children's Cystic Fibrosis Clinic Webpage? It's simple!

Click here: <http://www.cookchildrens.org/CF Center>

- Visiting our cystic fibrosis center
- Defining cystic fibrosis
- Meet our cystic fibrosis team
- Cystic fibrosis testing and diagnosis
- Treating cystic fibrosis
- Clinical trials and cystic fibrosis research
- Cystic fibrosis education and family resources- You will find all the latest CF newsletters here!



# Something to think about... CF Scholarships!



It's never too early to think about applying for scholarships for the next school year! A multitude of scholarships are available for those high school or college students living and thriving with cystic fibrosis. Deadlines may have already passed, but take a look at the scholarships that are of interest and review for future application.

Take a look at [www.CFRI.org/scholarship](http://www.CFRI.org/scholarship) or [www.esiason.org/cf-living/scholarships](http://www.esiason.org/cf-living/scholarships) for a detailed list and description.

- [\*\*AbbVie CF Scholarship\*\*](#)

#### **Eligible Applicants**

For those with CF who are high school seniors, vocational school students or college students enrolling in higher education.

#### **Award**

\$2,500 for the upcoming academic year.

#### **Additional Information**

<http://www.abbviecfscholarship.com/>

- [\*\*Jerry Cahill You Cannot Fail Scholarship\*\*](#)

#### **Eligible Applicants**

Applicants must have cystic fibrosis and must already have completed at least one semester of undergraduate coursework. Applicants must demonstrate that they go "above and beyond" in everything they do, displaying outstanding character, leadership and service to the community. They also must be compliant to their CF therapies and engage in regular exercise as part of their effort to stay healthy. Finally, applicants must demonstrate a need for financial assistance.

#### **Award**

\$5,000

- [\*\*The Boomer Esiason Foundation General Academic Scholarships\*\*](#)

The Boomer Esiason Foundation (BEF) General Academic Scholarships assist CF patients pursuing undergraduate and graduate degrees. Grants are awarded quarterly on the basis of demonstrated need and academic accomplishment.

#### **Eligible Applicants**

For students with CF undergraduate and graduate degree

#### **Award**

\$500 to \$2,500

#### **Deadlines**

Scholarships will be awarded quarterly:

March 15, June 15, September 15, December 15

#### **Additional Information**

Email: [jcahill@esiason.org](mailto:jcahill@esiason.org)

<http://www.esiason.org/cf-living/scholarships/bef-general-academic-scholarships>

- [\*\*The Boomer Esiason Foundation Sacks for CF Scholarship\*\*](#)

Sacks for CF funds are awarded annually to 30 college students, based on their academic achievements and adherence to daily CF therapy.

#### **Eligible Applicants**

Current and prospective college students with CF.

#### **Additional Information**

<http://www.esiason.org/cf-living/scholarships/sacks-for-cf-scholarship>

- **Exercise for Life Athletic Scholarship Program; Presented by The Boomer Esiason Foundation**

The Boomer Esiason Foundation (BEF) has created a scholar-athlete award to assist cystic fibrosis (CF) high school senior athletes pursuing undergraduate degrees.

**Eligible Applicants**

For undergraduate students with CF:

**Award**

BEF will grant one female and one male with a \$10,000 grant.

**Deadline**

June 10, 2016

**Additional Information**

<http://www.esiason.org/cf-living/scholarships/exercise-for-life-athletic-scholarship>

- **Cystic Fibrosis Lifestyle Foundation (CFLF), Recreation Grants**

**Eligible Applicants**

For all with CF

**Awards**

Recreation grants: \$500

**Deadline**

March 31st, June 30th, September 30th, December 31st

**Additional Information**

Email: [info@cflf.org](mailto:info@cflf.org)

<http://www.cflf.org>

- **Cystic Fibrosis Scholarship Foundation (CFSF)**

**Eligible Applicants**

For those with CF who will be enrolled in an undergraduate program or vocational school.

**Award**

Both single year and multi-year awards are made, generally for \$1,000 per year. Students may reapply the following year for an additional award, but are not guaranteed future awards.

**Deadline**

March 23, 2016

**Additional Information**

Scholarships will be awarded based on a combination of financial need, academic achievement, and leadership. Awards may be used for tuition, books, and room and board. Awards will be sent directly to the institution that the student is attending.

<http://cfscholarship.org/scholarships/>

- **Elizabeth Nash Foundation**

**Eligible Applicants**

For those with CF who are in-going or current undergraduate or graduate students at an accredited US-based college or university. The program is currently open to US citizens only.

**Award**

\$1,000 to \$2,500

**Deadlines**

April 4, 2016

**Additional Information**

Please direct any questions to [scholarships@elizabethnashfoundation.org](mailto:scholarships@elizabethnashfoundation.org).

- Any many, many, more... Check out [www.cfri.org/scholarship](http://www.cfri.org/scholarship) or [www.esiason.org/cf-living/scholarships](http://www.esiason.org/cf-living/scholarships) for a detailed list.

# In the News...



September 10, 2016 - The Shops at Highland Village

Get your wheels in motion and join us for our annual DFW CF Cycle for Life as we ride through some of the most picturesque and scenic terrain in the Shops of Highland Village. CF Cycle for Life is a fully-supported ride with route options of 30-60 miles. For more information visit: [cycle.cff.org](http://cycle.cff.org)



## Climb Details

**Date:** August 13, 2016

**Check-in:** 8:00 AM

**Start Time:** 9:00 AM

**Number of Steps:** 20 or 40 Floors

**Location:** Pier 1 Imports Building,

Fort Worth, TX

### **Event Coordinator**

**Name:** Jennifer Ulich

### **Event Coordinator**

**Email:** [julich@cff.org](mailto:julich@cff.org)

### **Event Coordinator**

**Phone:** 817-249-7744

### **Fundraising**

**Minimum:** \$150.00

## DFW CF FAMILIES



Come find us and like us on Facebook!

Click here:  
<https://www.facebook.com/DFW CF Families>

DFW CF Families page was created for those that are affected by the genetic disease Cystic Fibrosis (CF). Patients, families & friends are welcome to join the group and share encouragement, challenges, prayer requests, fundraising events, etc...





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 Hirannattana, 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:

- Sarah Lang, CCLS 682-885-4892

#### Social Services

- Aditi Prabhakar 682-885-3991

#### Research Nurse:

- Heather Urbanek (Heather Leach, research associate) 682-885-1244
- Courtney Wolff 682-885-2672

#### Clinical Therapist:

- Mariah Snapp 682-885-2720

### Cook Children's Medical Center and Cystic Fibrosis Center

#### Pulmonary Services:

1500 Cooper St  
Fort Worth, TX 76014-2724

Phone: 682-885-6299, Fax: 682-885-1090, Email: [www.cookchildrens.org](http://www.cookchildrens.org)