

# Cystic Fibrosis Newsletter

## Mark Your Calendars

### AUGUST 26, 2019:

CFF Golf Invitational (The Glen Club, Glenview, Illinois)

### OCTOBER 2019:

October 5: Great Strides Walk (Tower Park, Peoria Heights)

October 26: Breath of Life Gala (Venue Chisca, Peoria)

### NOVEMBER 20, 2019:

OSF/CHOI CF Center Family Education Night (Jump Trading Simulation & Education Center, Peoria)

## Clinic Accreditation Site Visit

The Cystic Fibrosis Foundation conducts CF center accreditation site visits every three to five years. We will be hosting surveyors for an accreditation site visit this year.

The Cystic Fibrosis Foundation helps fund and support CF Care Centers that meet established care standards. Site visits help assess clinic processes, clinic space and staff competence to determine if CF centers are meeting the standards set by the Cystic Fibrosis Foundation.

Surveyors usually are physicians from CF Care Centers from across the country. The site visit takes one day and reviews everything from hospital administration support of the CF clinic to infection control process followed during your clinic visits.

We are looking forward to hosting our accreditation site visitors, scheduled for Tuesday, October 1.



## Cystic Fibrosis Foundation Care Center Registry Report

Every year, the Cystic Fibrosis Foundation releases a report of the information entered in the CF Foundation Patient Registry. This report shows national averages for markers of health and disease severity in CF (infection rates, percentage of predicted FEV1 value, BMI, enzyme dose, frequency of medications, etc.) and helps centers understand where they are excelling and identify areas for improvement.

Here is a summary of our results:

- BMI for children 2-18 years of age was rising by five points annually from 2015-2017 to a maximum of 56 percent, which is excellent. There was no additional increase in 2018. Adult BMI remained on target.
- FEV1 percentage predicted for all age groups was almost at national average.
- The pediatric MRSA infection rate declined last year. Pseudomonas infection rate remained stable below national average.
- The percentage of patients achieving the four clinic visits per year remained stable at 60 percent, which is at



national average.

## New Faces at Adult Clinic

We now have physical therapy at adult clinics. Three therapists will be at clinic on a rotating basis. They are all very excited to have the opportunity to work with our CF center and provide specialized CF physical therapy care. Please join us in welcoming our new team members!

### CATHERINE "KATE" HORST, PT, DPT, CERT. MDT

#### Hometown:

"I'm from Peoria and have lived in Central Illinois my whole life."

#### Favorite food:

"I love ALL food but really love pizza and chocolate chip cookies!"

#### Hobbies:

"I have three daughters (ages 15, 12, 8), an amazing husband, a dog, and a cat. I also play French horn at church and a couple of community bands, and I run so I can eat more pizza."

#### What interested you the most in working with CF?

"I have been an outpatient PT for 20 years and love getting to know my patients. I have learned that a multidisciplinary approach is the best way to help the people we care for and effective education is the most important intervention we can provide. I used to be part of a multidisciplinary cancer rehabilitation program at IPMR, so I'm excited to be part of the adult CF team!"

### MEAGAN NEWQUIST, PT

#### PT background:

"I have been a PT for eight years in the outpatient world. I went to school at Clarke University in Dubuque, Iowa. I did both my undergrad and grad school there so I got to know the area quite well. I am originally from Wisconsin, so I always like to joke I am making my way around the Midwest."

#### Hobbies:

"I have a dog named Lucy who is definitely spoiled rotten, but she keeps me active as she loves to go on walks. I really enjoy reading and am always looking for a good book. I tend to have quite a few unread books on my book shelf at any given point because I buy them faster than I can read them!"

#### Favorite food:

"I don't know if I have a favorite food, but when I go out to eat, I really love Mexican. I think I have tried out most all the Mexican restaurants in the area!"

#### What interested you the most in working with CF?

"I am very excited to be part of the interdisciplinary adult CF team and to help get patients moving and active!"

### BRITTAN ROONEY, PT, DPT, OCS

#### Hometown:

"I am from Peoria, Illinois and went to Peoria Notre Dame High School."

#### PT background:

"I went to Loras College for undergrad where I played college soccer and graduated with a bachelor's in biology. I then went on to Creighton University in Omaha, Nebraska and completed my doctorate in physical therapy. Ever since graduating in 2015 I have practiced in the area of orthopedics and have now been with OSF for four years. In 2018, I received an additional board certification by the ABPTS in orthopedics."

#### Hobbies:

"I coach girls' varsity soccer at Peoria Notre Dame High School and have been doing this for four years. I have a background in strength and conditioning with high school athletes as well. I am running my first half-marathon this summer. I also have a twin sister!"

#### Favorite food:

"My favorite food is anything with cheese on it!"

## Quality Improvement Updates

### LUNG TRANSPLANT QUALITY IMPROVEMENT PROJECT

Our center has been invited to join the Loyola Medicine Transplant Center in a quality improvement initiative. This project is part of the CF Foundation's collaboration with Dartmouth to empower CF care centers. The goal is to teach CF care centers how to do quality improvement with the goal of improved outcomes for patients.

Team members from the adult OSF HealthCare CF Center care team will work with the Loyola team to coordinate care for those who are referred for a lung transplant. We will have regular meetings with the Loyola team, and we will be evaluating our processes and communication between the centers.

### SUMMER ACTIVITY STEP CHALLENGE

During the quarterly CF Center patient appointments, our staff at OSF HealthCare Children's Hospital of Illinois Cystic Fibrosis Center has been actively surveying patients (ages 8-18) on their physical activity throughout the school year. Our goal is to achieve a baseline physical activity level for patients and work with those individuals who need to improve on increasing physical activity.

Exercise and physical activity have been shown to have many benefits for children and adults. It also can be even more beneficial for individuals with Cystic Fibrosis. The Cystic Fibrosis Foundation recommends children should get a minimum of 60 minutes of moderate to vigorous physical activity daily. This does not have to be 60 continuous minutes of exercise, but can be spread throughout the day. There are many types of physical activity: running, jumping, climbing, ball games, resistance training (with bands or weights), swimming, biking, etc. Below are a few benefits and reasons to participate in physical activity:

- Better overall health: Exercise can help prevent various chronic illnesses such as heart and bone disease, diabetes and cancer.
- Better lung function: In addition to your current respiratory treatments, exercise also can help assist getting mucous out of your airways.
- Increased energy: Physical activity results in improved heart, lung, bone and muscle strength and function. Thus,



exercise can give you more energy and ability complete your daily activities and hobbies you enjoy.

- Enhanced mood: Exercise can allow you to be involved in a team environment, socialize and also help improve overall mood.

To make activity fun, we rolled out our very first Summer Activity Challenge for children ages 7-19 years old. The challenge started on June 3 and lasts until July 28. We had 22 participants sign up, and over 60 percent are meeting their weekly goals. We are excited for the strides patients are making toward their activity goals during this Summer Activity Challenge. Our CF Center is hopeful we can help you improve your health by increasing physical activity.

### Back to School Tips and Tricks

Summer is half over and it's time to start thinking about going back to school. Some reminders to help you start the school year right:

1. Avoid those drinking fountains! Be sure to take bottles of water to school so you aren't tempted to stop at the drinking fountain when you are thirsty.
2. School forms for enzymes and medications -- friendly reminder to get these to us early.
3. Don't forget to bring snacks! Here are some ideas for quick and easy high-calorie snacks:
  - Trail mix
  - Peanut butter and fruit or crackers
  - Pretzel and hummus snack pack
  - Cheese and nuts snack pack
  - Pre-made guacamole cups with tortilla chips or vegetables
  - Peanut butter and jelly sandwich
  - Yogurt, fruit, granola -- check out pre-made yogurt plus mix-ins such as Chobani® Flip®



## Heading Off to College?

Here are some things to keep in mind:

1. Decide if you are going to return home for your quarterly CF center visits or transfer to a new center closer to school.
2. If prescriptions are filled via mail order, call the mail order pharmacy with your new address.
3. Consider moving your prescriptions to a retail pharmacy near school instead of using your pharmacy at home (especially if it's a long drive to return home).
4. If you need to establish care at a CF center closer to college, make sure to request your records be sent to the new center. Also, make sure you have enough of your medications -- the new center will not be able to refill your prescriptions until your first appointment with them.

## High Calorie Recipe

For a quick treat that is not only high in calories, but very easy to make, try these flavor-packed peanut butter protein bites. These protein bites can be taken to school, work, camp and also are a great snack to eat before a workout, practice or sporting event. If you are living on the wild side, you can try substituting the peanut butter with another nut butter or even sun-butter. You also can customize this recipe even further by adding M&M's, Reese's Pieces, dried fruit, coconut or other tasty treats of your choice. This recipe also calls for ground flax seed, which can be an easy way to add fiber to your diet. If you take pancreatic enzymes, please note this snack has 23 grams of fat. Enjoy!

## PEANUT BUTTER PROTEIN BITES

Prep time: 10 minutes

Total time: 40 minutes (including cooling time)

Portions: 8

Serving size: 1 protein bite

### Ingredients:

1 cup creamy peanut butter

one-half cup semi-sweet chocolate chips

1 cup old-fashioned oats

one-half cup ground flax seeds

2 tablespoons honey

### Directions:

1. Combine all five ingredients in a medium bowl. Stir to combine ingredients thoroughly.
2. Place mixture in the refrigerator for 15-30 minutes to make the protein bites easier to roll.
3. Roll into eight even-sized bites.
4. Enjoy!

### Nutrition Facts:

Calories: 330

Total fat: 23 g

Sodium: 140 mg

Total carbohydrate: 27 g

Protein: 10 g