

# Cystic Fibrosis Newsletter

Spring, 2017  
Volume 2, Issue 2

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### Chocolate-Peanut Butter Shake Recipe

- 1/2 c. heavy whipping cream
- 3 tablespoons creamy peanut butter
- 3 tablespoons chocolate syrup
- 1 1/2 c. chocolate ice cream
- Handful of ice

Blend in blender.

1070 calories/shake



## Summer Preparations

Can you believe that summer is fast approaching? In just a few short months several of our patient's will be finishing the school year and enjoy the summer months. As the Florida hot and humid summer approaches, our patient's with CF need to be careful as they typically do not tolerate heat well. Young children do not sweat as much as adults making it harder for their bodies to cool off. In addition,

patients with CF lose more salt in their sweat. Because more salt is lost, it is important for patient's to replace not only the fluid loss, but also the salt. Drinking sport drinks with electrolytes can assist with this loss of water and salt. Eating foods high in salt such as pretzels, potato chips, and salted nuts will help patient's replace the sodium lost. Stay hydrated, and drink lots of water!

During the summer it is important to wear sun screen to protect skin from harmful sun rays. You should wear sunscreen whenever outside, including cloudy or rainy days. Sun screen decreases the risk of developing skin cancer.



## Great Strides

The Cystic Fibrosis Foundation strives to raise money each year to support the Foundation's mission to cure cystic fibrosis and raise awareness. Great Strides is the Cystic Fibrosis Foundation's largest national fundraising event. The CF Foundation utilizes this fundraiser to perform innovative research and drug development, promote high-quality,

individualized care, and help people with CF live better today's. The Foundation has made nearly every CF medication possible which has assisted with patient's living longer, healthier lives.

Great Strides is located in 4 counties in Central Florida this year. The dates and times are as follows:

Saturday, April 22, 2017  
Orlando- Harbor Park at Lake Baldwin

Saturday, May 6, 2017,  
Lake Nona- Moss Park

Saturday, May 20, 2017,  
Brevard County- Wickham Park and Volusia County- Frank Rendon Park

We hope to see you at our Arnold Palmer Cystic Fibrosis table!



## Bubble PEP (Positive Expiratory Pressure)

PEP (Positive Expiratory Pressure) therapy is a way to get air into the lungs and behind the mucus prior to breathing out against a resistance. Utilizing the PEP helps air get behind the mucus and helps move it from the lungs. A fun way to perform PEP therapy is utilizing a bubble PEP. A bubble PEP works via blowing into tubing (straw) against a resistance (water). Making a bubble PEP is fun and easy.

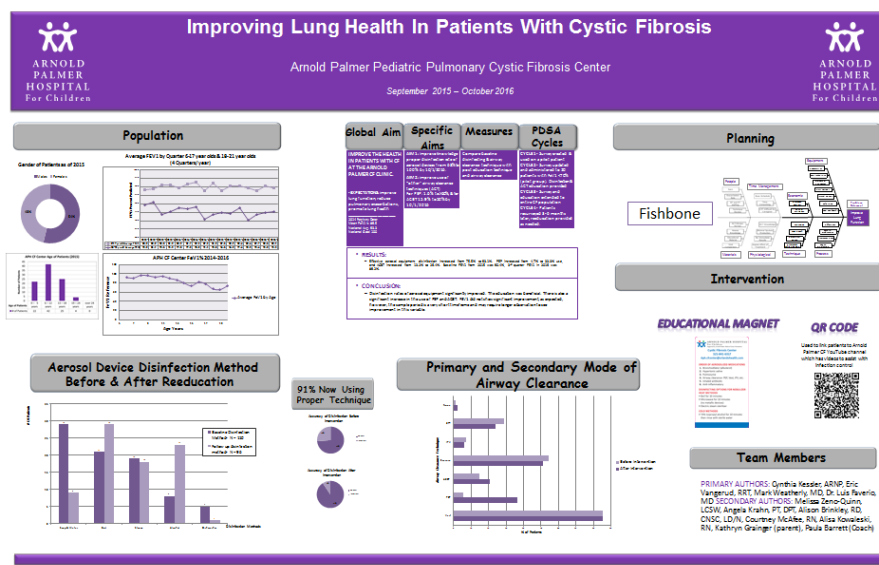
### Set Up:

1. Fill a bottle, pan, cup, or container with distilled water (approximately half full) and add something to make blowing into it fun (i.e. liquid soap, food coloring).
2. Put the straw or plastic tubing into the water.

### Instruction:

1. Take a breath in.
2. Hold for 3 seconds.
3. Blow out through the tubing/straw as long as you possibly can.
4. If performing in a bottle (such as a plastic water bottle), see if the patient can blow the bubbles up out of the water bottle.
5. Repeat 10 times.
6. Huff Cough.
7. Repeat the cycles 2 more times.
8. After each use, throw away plastic straw or clean it with alcohol and distilled water.

## Our Most Recent Poster Presentation!



## HealthWell Update

Effective April 10, HealthWell Foundation, an independent nonprofit financial support organization, will provide patient assistance for people with cystic fibrosis through two separate funds: a treatment fund and a vitamins and supplements fund. The treatment fund will cover CF treatments, hypertonic saline, and some paired nebulizer systems and handsets. The vitamins and supplements fund will cover certain vitamins and supplements that people with CF need to stay healthy. People with CF enrolled in HealthWell's fund prior to April 10 will continue to access available services through

their existing grant until the end of their enrollment period (one year from their enrollment date). New enrollees or people who are re-enrolling should apply for the treatment fund and/or the vitamins and supplements fund as needed.

**Healthwell's eligibility income qualifications have also changed with this new split in assistance. Please check the website for details.**

For questions related to this change, please contact HealthWell by phone at (800) 675-8416 or by email at [grants@HealthWellFoundation.org](mailto:grants@HealthWellFoundation.org)



## Administering Orkambi

We have had a few questions regarding the administration of Orkambi. Orkambi should always be taken with fat-containing foods as they help the body absorb the medication better. Some examples of fat-containing foods your child can eat when taking Orkambi include: Eggs, macaroni and cheese, nuts, pudding (no low or reduced fat), butter, hummus, avocado, salmon, cheese pizza, peanut butter, whole milk dairy products (such as whole milk, milk shakes, ice cream, cheese, and yogurt).

### Examples of Fat-Containing Foods<sup>1</sup>

Fat-containing foods help the body absorb ORKAMBI better. A typical CF diet will satisfy this requirement. When counseling patients, this list provides examples of a variety of fat-containing foods to take with ORKAMBI

- Almonds
- Avocado
- Cheese pizza
- Deli ham
- Eggs
- Granola

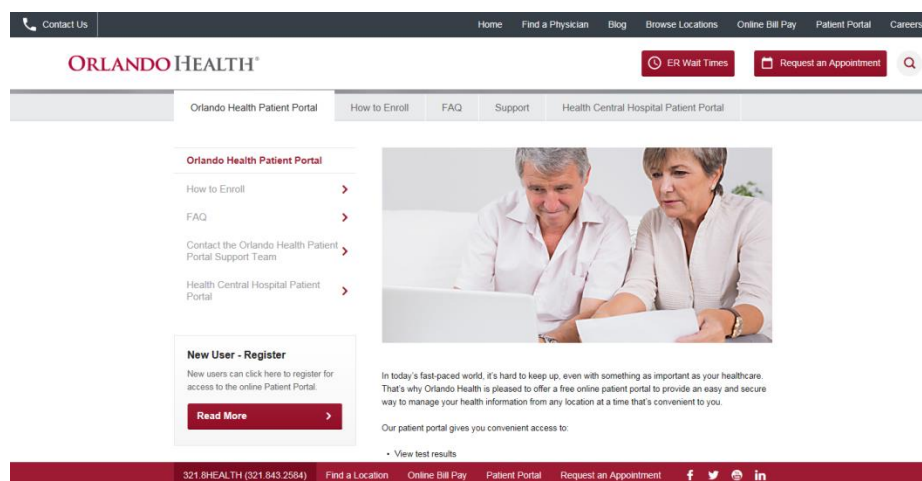
- Hummus
- Nuts
- Peanut butter
- Roasted peanuts
- Salmon

- Trail mix with nuts
- Tuna
- Whole milk
- Whole-milk cheese
- Whole-milk yogurt

## Orlando Health Patient Portal

The Orlando Health Patient Portal allows families manage their child's personal medical records, view lab and test results, and view upcoming appointments. To obtain access to the patient portal, provide your e-mail address at your next CF visit. After signing up, you will receive an e-mail from [NoReply@FollowMyHealth.com](mailto:NoReply@FollowMyHealth.com) asking you to register on the

MyOrlandoHealth.com portal. Click on the registration link in the e-mail. Then, proceed to create an account. If you have any questions, please contact us or e-mail [SupportPatientPortal@OrlandoHealth.com](mailto:SupportPatientPortal@OrlandoHealth.com) or call 321-843-7759. If you need to contact your CF teams please e-mail us at [aph.cfcenter@orlandohealth.com](mailto:aph.cfcenter@orlandohealth.com).



## CF R.I.S.E.

Are you 15 years of age or older? If you are, please be on the lookout for information on CF R.I.S.E. CF R.I.S.E. is a program to help patients with CF assume more responsibility for their care. The program is designed to help patients, parents, and care teams manage the transition and transfer process from pediatric to adult care. The program assesses patient CF knowledge on various topics to help your care team determine where additional support and education is needed. Patient learning modules are provided as well as learning assessments.



**Please fax school forms for administering medications and health information for the upcoming 2017-2018 school year, to 321-843-6659 and contact Melissa at [Melissa.Zeno-Quinn@orlandohealth.com](mailto:Melissa.Zeno-Quinn@orlandohealth.com) for questions and concerns to make sure that your child starts off the school year right.**

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