



# Breath of Fresh Air

## Cystic Fibrosis Foundation Great Strides Walk 2016

Each year the Cystic Fibrosis Foundation (CFF) hosts the Great Strides Walk. This year the event was held at Louisville Slugger Field on Saturday, May 21, 2016. It was a 5K walk which started at Slugger Field and wound around the Ohio River. There were several vendors that had information about products, medications, and there were items for sale as well. Doughnuts were generously provided by Thornton's before the walk and Papa John's was gracious to provide pizza after the walk. It started to rain that morning but fortunately the rain quit right before the walk began.

Most of the Great Strides Walks take place in May in many different cities each year. The Great Strides Walk is a way for anyone and everyone to get involved to show their support and to help raise money for those fighting this disease. If you are looking for an easy way to get involved, this may be for you. You can sign up as an individual or with a team. There are prize incentives based upon the amount of money that you are able to raise. This event would not be possible without the help of so many volunteers. If you would like to get involved



you can contact the local CFF KY/WV Chapter at (502) 454-8435 or (800)526-8126.. They would be happy to have you help with next year's walk. As the saying goes "Many hands make light work."



## Cystic Fibrosis Related Diabetes

Cystic Fibrosis Related Diabetes (CFRD) is a certain type of diabetes that only people with cystic fibrosis develop. In Type 1 Diabetes the body does not make insulin. In Type 2 Diabetes, which is usually diagnosed after the age of 40, the

body does not respond normally to the insulin that is made or it does not make enough insulin. CFRD is different in that the body can't make or use insulin the right way so more is needed to convert food into fuel and keep your blood sugar in the

normal range. Every single person's goal regarding diabetic treatment is to have a blood sugar level that is as close to normal as possible.

Unlike Type 1 & 2 Diabetes, with CFRD your calories are not limited.

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### CFRD Symptoms:

- Polyuria (excessive urination)
- Polydipsia (excessive thirst)
- Feeling very tired
- Losing weight
- Not able to gain weight
- Loss of lung function

Talk to your doctor if you are experiencing these symptoms.

## New Clinic Schedule

In May, we started scheduling patients for appointments at 1 p.m., 3 p.m. and 4 p.m. We are hopeful that this new schedule will facilitate a better clinic experience and level of satisfaction for our patients. In an attempt to keep your wait time at a minimum, some patients will be placed in exam rooms, after they have signed in, while others will go to have their Pulmonary Function Test (PFT) done. The patients that were placed in exam rooms will be seen by other members of the CF team and

then will have PFT's done as well. Please let us know if you have been waiting longer than 10 minutes. We would like to hear your suggestions and look forward to seeing you in clinic.

Dr. Sathya Krishnasamy, Endocrinologist, sees patients the first Monday of each month who have diabetic or bone health issues.



## The Medicine Corner- Pulmozyme What it is and why you take it.

Pulmozyme is a medication that is inhaled as a mist with the use of a nebulizer. The majority of patients with cystic fibrosis take this medication either once or twice a day. This medication, also known as dornase alfa, helps to thin the secretions and lessen the risk of developing a respiratory infection. Pulmozyme should not be mixed with any of your other medications. It should be kept in the refrigerator and protected

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from strong light. It does not contain a preservative. So, after it is opened it should either be used or discarded. If you are having problems affording this medication please let us know.

## Welcome Summertime!

Summertime is here and we all like to be outside to enjoy the warm weather. Whether you are playing in the pool, barbecuing for friends and family, playing a sport, or mowing the lawn, remember the following important tips. The UV rays are strongest between the hours of 10 a.m. and 4 p.m. ET. The Centers for Disease Control & Prevention (CDC) recommends that you use a sunscreen with

SPF of 15 or higher that blocks out the UVA and UVB rays, Reapply after a couple hours and be sure to check the expiration date. Loose fitting clothing offers the best protection from the UV rays. Wear sunglasses and a hat to shield yourself from the harmful rays. Most importantly, remember to stay hydrated by drinking plenty of water and eat extra salt because you lose more



in the Summer due to sweating. Store medications at a safe temperature.

## Mental Health Screening

The Guidelines Committee on Mental Health (GCMH) jointly formed by the CF Foundation and the European CF Society developed recommendations for screening individuals for depression and anxiety. This committee was formed because it was found that a large number of CF patients and their caregivers were at a higher risk of developing symp-



toms of anxiety and depression. When you come to the CF Clinic you may be asked to complete a PHQ-9 (Patient Health Questionnaire) and a GAD-7 (Generalized Anxiety Disorder) questionnaire. These tools are quick and easy to complete and are highly reliable tools. A qualified member of the CF Team will administer the tool, explain it, answer

any questions you may have about it and then go over the results with you. These tools will be part of your permanent medical record but it will be confidential and private, like your other information. We strive to follow guidelines regarding regular clinic visits, sputum cultures, xrays, and pulmonary function tests. In order to provide the best care possible, we need to make sure that we are assessing your overall health. Mental health is just as important as your physical well being.

## Connection Between Weight and Lung Function

The importance of good nutrition is well known in the CF Community: people with CF who weigh more, are taller, or have higher BMI's have better lung function and live longer. It is not exactly known why this is, however the CF Foundation encourages patients to work closely with their care center to achieve BMI goals. BMI is calculated by dividing weight in kilograms (kg) by the person's height in meters squared. You can also calculate

it on the CDC's website at: [www.cdc.gov/healthweight/assessing/bmi](http://www.cdc.gov/healthweight/assessing/bmi). A BMI of 23 is recommended for men and a BMI of 22 is recommended for women. To improve or maintain your weight, the CF Foundation suggests that you work closely with your CF Center. To learn more about CF and nutrition, ask your CF care center or visit [www.cff.org](http://www.cff.org).

**"For success, attitude is equally as important as ability."**

**-Walter Scott**

## Meet Your Dietitian-Shari Willy

Shari Willy, RD, LDE graduated with her Bachelor's of Science degree in dietetics from Purdue University in West Lafayette, IN and completed her internship there as well. In September 2000, Shari began working as a clinical dietitian at Norton Hospital and Kosair Children's Hospital with a focus in adult and pediatric hematology and oncology nutrition. In January 2005, she transferred

to Suburban Hospital and worked in management capacities. She returned to the clinical nutrition realm in 2007 at Norton Audubon Hospital. She joined the Pediatric CF Clinic in January 2008 and the Adult CF Clinic in September 2008. She resides in Louisville with her husband, son, and two pets. In her free time she enjoys spending time with her family, running, and traveling.



**U of L Adult CF Center**

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**Important Numbers to Know**

U of L Cystic Fibrosis Clinic Office Main Number (502)588-4600

Kay Burris, RN (clinic coordinator)- (502)852-1080

After hours Clinic number to reach a physician- (502)588-4600

HealthWell Foundation (patient assistance )- (800)675-8416

CF Foundation Compass- (844)COM-PASS

CF Services Pharmacy- (800)541-4959

Foundation Care Pharmacy- (877)291-1122

Hill Rom (vest)- (800)426-4224

**CF PATIENTS ARE ADMITTED TO JEWISH HOSPITAL**

**What's Cooking?**

**Breakfast Pizza**

**Ingredients**

- 1 can refrigerated pizza crust
- dusting of flour for pizza crust
- 1 tsp. olive oil
- 8 slices of bacon (crisply cooked)
- 8 eggs
- ½ cup of half and half
- ½ tsp. salt
- ½ tsp. pepper
- 2 Tbsp. butter
- 1 container chive, vegetable, or regular cream cheese
- green onion (if desired)
- grated cheese of choice

**Directions**

- Preheat oven to 425° F.
- Dust pizza pan with flour. Unroll pizza crust and place in pan. Starting at center, press dough out with hands to edge of pan.
- In 10 in. skillet, add olive oil and cook bacon over medium-high heat until mostly done. Remove bacon and leave fat in skillet.
- In medium bowl, beat eggs, half and half, salt, and pepper.
- In same skillet, melt butter and add egg mixture.
- As eggs are getting done, add cream cheese to skillet and stir.
- Cook and stir until thoroughly cooked but still moist. Remove from heat.
- Spoon egg mixture over crust and layer bacon on top.
- Bake 12-15 minutes until thoroughly heated and crust is golden brown.
- Garnish with green onion and grated cheese.

**Notes:**

Below are easy substitutions you can make to lower the calorie count for breakfast pizza when cooking for people without CF.

INGREDIENTS	SUBSTITUTION	CALORIES SAVED
8 slices of bacon	4 slices of bacon	172
8 eggs	4 eggs	284
½ cup half and half	½ cup skim milk	115
1 container cream cheese	1 container ½ less fat cream cheese	70
2 Tbsp. butter	cooking spray (3 sprays)	197

- In step 3, drain bacon fat in skillet
- In step 4, add skim milk instead of half and half
- In step 5, use cooking spray to coat skillet instead of melting butter

Recipe compliments of Actavis program Live2Thrive

