

Breathe Strong

A quarterly interactive publication for adults living with cystic fibrosis

Welcome Our New Team



The Emory Adult CF Program is proud to present our newest team member, Andrea Terrell, LPN.

Andrea is from Columbia, South Carolina. She was raised in Omaha, Nebraska. She moved to Atlanta during her senior year and graduated from Decatur High School.

Andrea received her nursing license from US Army Nursing Program in February 2012. Her clinical experience includes Pediatrics, ICU, Medical-Surgical and Dialysis. Andrea's favorite movie is The Blindside and her favorite color is purple. She enjoys reading, running, skating and trips to the beach.

We are excited to have her as a part of our team!

-Emory Adult CF Team

CF Family Education Day 2015

It's that time again. The second annual combined CF Family Education Day is scheduled for Saturday, April 25, 2015. We are excited to provide patients, family and friends and caregivers with the opportunity to learn about beneficial topics. Some of this year's topics include:

- **Winning with CF**
- **Genetics- ins and outs of CF Mutation**
- **Clinical trials/drug pipeline**
- **Understanding CF cultures**

Registration is recommended at the following link: <http://goo.gl/forms/MaoPo83slp>

The event will include breakfast, lunch and helpful handouts.

The location of the event is

Starvine Ballroom
Emory Conference Center & Hotel
1615 Clifton Road NE
Atlanta, GA 30329

To view the complete event flier, see page 4

WANDERINGS FROM THE WEB:

- ♦ [CF Research, Inc. \(CFRI\)](#)
- ♦ [Club Cystic Fibrosis-Online Community for Adults](#)
- ♦ [CF Blog- Sarah Joys of CF](#)
- ♦ [CF Blog- Dreaming of Breathing](#)
- ♦ [Update on Vertex Phase 3 Combination Study](#)
- ♦ [CFF Recommends Against Using Peppermint Oil in Nebulizer](#)
- ♦ [Emory Adult CF Program: Achieved Newsletters](#)

To access the websites here and within this issue, hover your mouse over the name of the site and click.

Nutrition Notes: Farmer's Market

I recently noticed daffodils popping up around the city, which means it is almost my favorite time of the year, spring! I love spring time mainly because it is not cold any more, but most importantly because farmers markets are re-opening for the season. Your neighborhood farmer's market is a great place to buy fresh, local, and seasonal produce. Plan a trip to the farmer's market closest to you, and I promise you (and your taste buds) will enjoy it.

Here are a few tips:

- Some farmer's markets have fresh coffee and pastries, so you can have a second breakfast! My favorite breakfast is a glass of hazelnut iced coffee from Blue Donkey Coffee with an almond croissant from H&F Bread Company at the St. Philip's farmers market.



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Emory Adult Cystic Fibrosis Patient & Family Advisory Council



The CF team is excited to introduce the newly created Adult Cystic Fibrosis Patient & Family Advisory Council of Atlanta, GA.

The council was created in the fall of 2014 under the direction of Shaina Blair, LCSW and Samone Williams, MSW Intern of The Emory Adult CF Program and consists of 8 members of the Emory CF community—5 adult patients and 2 caregivers.

The mission of the Emory Adult Patient & Family Advisory Council is to collaborate with Emory Healthcare team to improve the clinic, hospital and outpatient care experiences of adult CF patients and families.

2014 Patient & Family Advisory Board Accomplishments

- Development of council mission statement

- Development of online meeting format using GoTo Meeting and a customized Shutterfly site for shared documents and message board communication
 - Consultation with other Advisory Councils in exploring best practices—Stanford University, Hartford Hospital, Children's Healthcare of Atlanta
 - Creation of council logo with an outside graphic designer
 - Collaboration with 6G staff in creation of a hospital handout for new patients
 - Review of patient education materials—"What To Expect for your First Clinic Visit", "What To Expect for your First Hospital Stay"
 - Collaboration in developing inpatient CF respiratory therapy protocol, including creation of an online patient survey
- collaboration with program social worker
- Contribute information/articles updates to adult program newsletter
 - Participation in planning 2015 Family Education Day

Want to get involved? Ask Samone Williams how to join the council sponsored Facebook page or email the council: atlantacfcouncil@gmail.com

-Ashley Faas

Current Goals/Projects

- Further development of council bylaws
- Creation of a closed Facebook page for adults with CF (ages 18 and older) who attend the Emory Adult CF Program in

Farmer's Market

- There will be other things besides fruits and vegetables. There is a wide variety of goods being sold. Be on the look out for dairy products, eggs, meat, jelly, honey, spices, and some even have cooked items, like falafels, soups and tamales. I happen to love the chocolate and sea salt popsicle from King of Pops at the Emory farmers market.
- Try something new! This is a great place to find different items that are not sold in regular grocery stores.
- Talk to the vendors. They can tell you more about their products, and even give cooking or recipe ideas. Some might even give you a sample! Yum!
- Remember your reusable bags. Many vendors have paper or plastic bags, but if you bring your own bag, you will be able to put more than one purchase in the same bag, making it easier to walk around. I also bring an insulated tote with an ice pack if I am not going home immediately. The jalapeno and white cheddar pimento cheese from Mad Mamma's Gourmet at the Brookhaven farmers market is a favorite at my house.
- Have cash on hand. A lot of vendors take credit/debit cards now, but if you have cash, the transactions are usually faster.

Tell me about your trip to the farmers market at your next clinic visit! I would love to hear about what you found and any recipes you tried. I know it will be delicious!

Be well!





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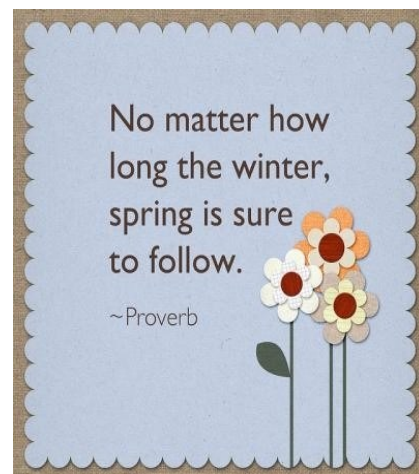
[www.emoryhealthcare.org/
cystic-fibrosis](http://www.emoryhealthcare.org/cystic-fibrosis)

Coughing is Cool! by Mews Hilaire, RRT

A step-by-step model for Airway Clearance

1. Bronchodilator (**ALBUTEROL/ATROVENT, XOPENEX, COMBINVENT**)
FYI! INHALERS (PUFFERS) WORK AS WELL AS NEBS
2. Hypertonic Saline with the Vest on. When done, pause & do 5 repetitions of the Acapella. (COUGH)
3. Pulmozyme with the Vest on. When done, pause & do 5 repetitions of the Acapella. (COUGH)
4. Continue with the Vest to complete a 30 minute cycle.
FOLLOW WITH 5 REPETITIONS OF THE ACAPELLA. (COUGH)
5. Once you're done with coughing, RELAX!
THEN USE: ADVAIR, FLOVENT OR SPIRIVA
6. Finish with: TOBI-OR-CAYSTON-OR-COLISTIN

SO LONG MUCUS!



Feature Article:

The views and opinions expressed in this article are those of the author and do not necessarily reflect the views of The Emory Adult CF Program or Emory Healthcare. The mention of any company, service, or therapy in this article does not constitute an endorsement by the Emory Adult CF Program or Emory Healthcare.



Atlanta Cystic Fibrosis Education Day

Saturday, April 25, 2015

Starvine Ballroom
Emory Conference Center & Hotel
1615 Clifton Road NE
Atlanta, GE 30329

This year marks our second annual combined CF Family Education Day for all three of our Atlanta Centers– Emory Adult, Children's at Egleston, and Children's at Scottish Rite. Family Education Day is intended to inform and educate everyone who is affected by Cystic Fibrosis, including parents, relatives, friends, and healthcare providers. All families from any CF Center are invited.

****Special Keynote Address****

Winning with CF

Lisa Greene, MA, CFLE

Author, Speaker, Certified Family Life Educator

Other presentations include:

Genetics- ins and outs of CF mutations

Anjana Varma

Genetic Counseling

Updates on Clinical Trials/ Drug Pipeline

Nael McCarty, PhD

Director, CF@LANTA

The Emory+Children's CF Center of Excellence

Understanding CF Cultures

Seth Walker, MD

Director, Emory Adult CF Program

There is no cost to attend but we ask that you register. We will provide handouts as well as breakfast and lunch. Childcare will NOT be provided.

Due to infection control risks to people with CF, we ask that no patients attend in person. The meeting will be recorded and available for viewing.

Sign-up to Attend: <http://goo.gl/forms/Ma0Po83sJp>

Email: CFFamilyDay@gmail.com

or call Jennifer Vazquez at 404-727-7358