

CF Family Advisory Council
ATLANTA, GEORGIA


The purpose of the CF Advisory Council is to work together with staff to advance the practice of family-centered care — the belief that healthcare providers and families are partners working together to improve quality care for patients. This is accomplished by designing better programs, policies and procedures that provide the best possible care and meet the needs of the CF patient and their families.

Let us hear from you.

- If you have newsletter story ideas
- If you or your child would like to be featured in the spotlight section
- Share your favorite recipe
- Nominate a CF Superhero
- Have questions or comments you would like FAC to address

Email to: stickynotesnewsletter@gmail.com


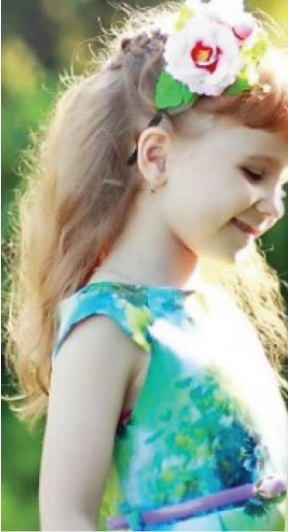
This information is provided to supplement the care provided by your physician. It is neither intended or implied to be a substitute for professional medical advice. Always seek the advice of a physician or other qualified health provider prior to starting any new treatments or with questions regarding a medical condition.




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ATLANTA, GEORGIA

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Atlanta, GA 30342-4722

To the parents of:





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Sticky Notes

Spring 2016

This Eating Stuff is Hard Work!

By: Pam Baker

We all know that having one (or two) child(ren) with cystic fibrosis can be a challenge in many ways, but who would have thought that FEEDING our children would be one of the biggest challenges of all!?! Feeding our children is a constant battle for most, so in January, the FAC hosted a CF nutrition night to address the challenges that it brings not only to the child with CF, but to the entire family. CF care center nutritionists Kanan Patel, Liz Revilla and Kaeti Lindsay led the evening offering tips on how to add healthy fat and calories to meals that can be served to the entire family along with some tasty samples. They also gave us a handout on how to navigate the grocery store aisles steering clear of unhealthy fats and processed food and adding healthier, affordable options. Shaina Blair, the Emory care center social worker, shared some helpful tips on the multiple nutrition assistance resources available to families - both income and non-income based. One of my favorite parts of the night, however, was when special guest speaker, Sabrina

Baker, age 10, shared with us the challenges that she has faced as the sibling to two brothers with CF. Sabrina explained that when she was younger, she didn't understand how important it was for her brothers and would often get very angry and feel like "it wasn't fair" that they got all of the attention AND all of the good food, but now that she's older, it makes a lot more sense to her. She definitely offered an insightful perspective for us! One final take away for the night was when Liz shared with us the division of responsibility when dealing with mealtime challenges. She explained that parents are responsible for the "what, when and where" of mealtime and children are responsible for the "whether and how much" meaning that the parents decide what, when and where the food gets served and the child decides whether to eat and/or how much to eat. Easier said than done, but following this rule of thumb should take the pressure off of BOTH the parents and the child!



CALENDAR OF EVENTS

March 12, 2016
ShamRockin' For A Cure

April 11, 2016
Danile B. Caplan Family Science Dinner

May 21, 2016
Great Strides Atlanta

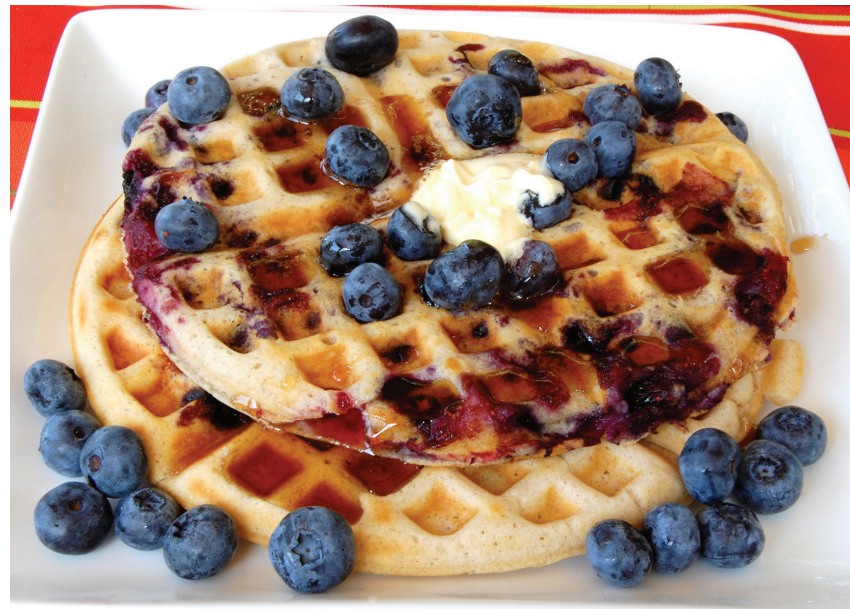
Patient Spotlight



Name: Zoey Ann Ray
Age: 4
Hometown: Braselton, GA

FAVORITES:

Food: Blueberry waffles
Movie: "Hotel Transylvania"
Book: any "Little Critter Books"
Color: Pink



Sport: "Go Braves!!" Baseball

One word that describes you: Playful

Accomplishment: Potty trained

Advice to others with CF: "Sit down and do your shake shake" (Respirtherapy)

One of your favorite things to do with your family:

Give hugs and kisses

Things to look forward to in future: Having friends over for get-togethers

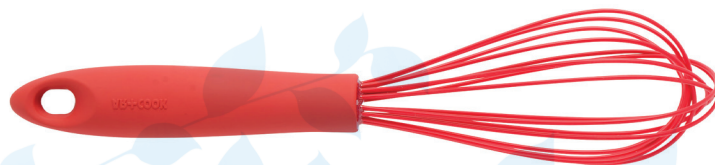
Your role model: Mommy and Daddy

Favorite staff spotlight: Dr Beaty

Pink Girl

Kid's
Corner

Cooking Together



Cooking together can be fun and very beneficial to your family. First find a recipe that you would like to try. Healthy foods like okra can be cooked or fried in a recipe that may not have been tried otherwise. Cooking together brings family together in the midst of rushed schedules and time away from TV. The benefits of cooking together are endless. So get started cooking together today!



CF SUPERHERO



Kaeti Lindsay
title.....

Where did you grow up?
Athens, GA

Who is your family?

Parents: Tammy and Duke Lindsay
Younger (but bigger) brother: Lake (Senior at The University of Alabama)

How long have you been in the field of CF?

1½ years. Beginning at Children's of Alabama Hospital (UAB Pediatrics CF Center)
Since July, 2015 @ Eggleston Outpatient CF Center (CPG PACS)

What was the decision that led you into the field of CF?

Pediatric Pulmonary Center Traineeship (8/2014-5/2015)
Fell in love with this patient population immediately. The disease requires a great deal of nutrition treatment and I enjoy developing a relationship with these patients I see every 3 months (sometimes more).

Where did you attend college?

Bachelor's Degree: The University of Georgia
Master's Degree: The University of Alabama at Birmingham

If you could have one superpower what would it be?

To fly! For the pretty views and simpler access to vacation destinations.

What is one thing you miss about being a kid?

Summer Break!

Name one word that describes you:

Driven.

What is one accomplishment that you are proud of?

Being hired into my dream job as a Children's Healthcare of Atlanta CF Dietitian!

List one thing that most people do not know about you?

I went to Auburn for my freshman year of college, despite being born and raised as a Georgia Bulldawg and living ¼ mile from the UGA campus. Came back to Athens Sophomore year to complete undergrad and will remain a Bulldawg until the day I die.



Links of Interest

cff.org

georgia.cff.org

milesforcysticfibrosis.org

reachingoutfoundation.org

choa.org/cf

happyheartfamilies.com

cfvoice.com

cysticlife.org

shamrockinforacure.com

Vitamin C Booster Smoothie

Ingredients:

1 cup frozen pineapple
1/2 cup orange juice
1 cup full fat vanilla yogurt
1 cup fresh, washed kale

Directions:

Put all the ingredients into a blender and blend until completely mixed.

Nutritional analysis (per serving)

Serves: 1 serving
Calories per serving: 500
Fat: 7 g
Sodium: 105 mg
Protein: 8 g
Calcium: 326 mg