



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.

To the parents of:

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Sticky Notes



Winter 2015

What does “Support” mean to you?

By Pam Baker

The word support can be defined in many ways. As a verb, it can be defined as “to bear or hold up” or “to sustain a person under trial or affliction. As a noun, support can be defined as “a person who gives aid or assistance”. Support can mean many things to many people, but those of us in the CF world know that support from families, friends and sometimes even total strangers can be the life line that holds our world together. We have all needed support from time to time –whether at initial diagnosis, first hospitalization or when your child transitions to adult care. The question then is where can we get the best support to help guide us through these sometimes terrifying waters? Families and friends are great, but can they provide us with the best help when these milestone moments occur? Oftentimes, the answer

is no. It’s not that we don’t appreciate them for what they can provide, but when it comes down to it – the person who can be of most help is the person who knows exactly what it feels like to walk in your shoes. So where do we find these other CF families and how can we connect with them you ask? Well...the Family Advisory Council is currently forming a Parent-to-Parent Network to do just that and we need your help! Our goal is to create a huge database of people with a wide variety of experience (from family planning to sending your child off to college and everything in between). Be on the lookout for our Parent Networking Event coming this fall and definitely make plans to join us because you never know how your support can change someone else’s life and you never know when you might need a little support yourself!

CALENDAR OF EVENTS



March 7
ShamRockin’ For a Cure
cff.org/chapters/georgia

March 22
Publix Georgia Marathon and
½ Marathon
milesforcysticfibrosis.org

GREAT STRIDES 2015
cff.org/great_strides
April 18 - Albany
April 25 - Augusta
May 16 - Columbus
May 16 - Rome
May 16 - Atlanta
June 13 - Macon

Patient Spotlight



Name: Sutton Grace Burnett
Age: 2
Hometown: Decatur, GA

FAVORITES:

Food: Bananas
Movie: Frozen, Frozen, and more
Color: Purple
Book: Pete the Cat books
Favorite Sport: Soccer
(with my pink Hello Kitty ball)

FROZEN



One word that describes you: Sassy

Accomplishment you are proud of: I can put my shoes on all by myself!

Advice you'd give other kids who have CF: Give each day 110%!

One of your favorite things to do with your family: Go to the zoo or the fire station

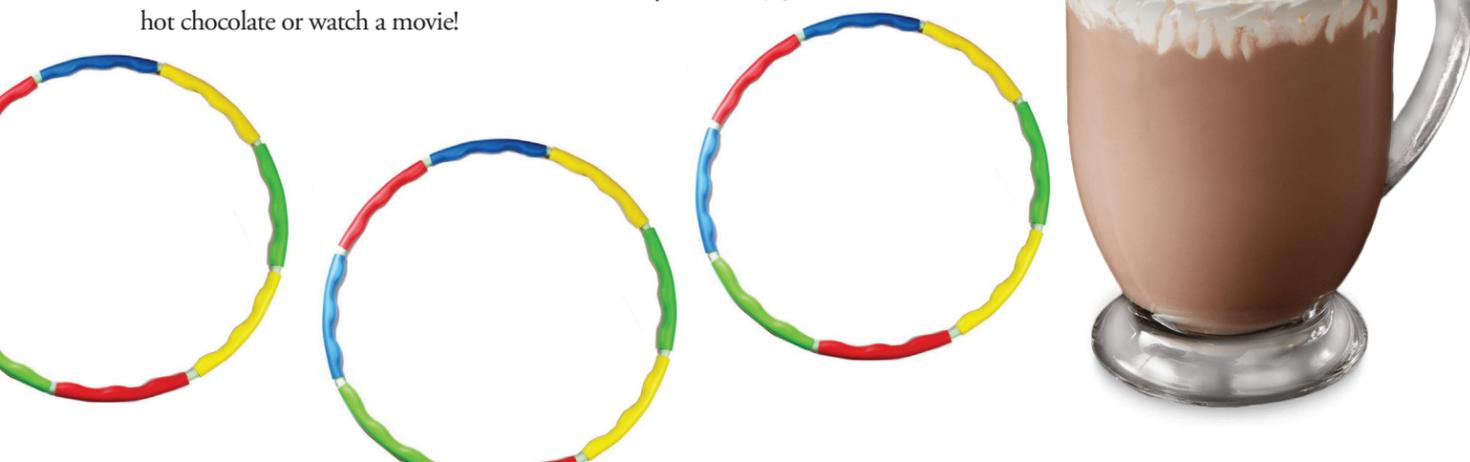
What you are looking forward to in the New Year: Going on my first beach trip!

Your role model and why: My 4 year old brother Hiatt-he makes me laugh a lot!
He also raises money to help us find a cure for CF.

Kid's Corner

Make Room!

Wondering how to keep your kids active and entertained when they can't play outside? Clear a space and then use your imagination to come up with a great obstacle course that will keep them busy for hours! Grab items like a tricycle or a scooter, blankets, a hula hoop, chairs, couch cushions, or laundry baskets to get started. Once everyone has gotten some energy out, use the same materials to create a winter fort where you can enjoy some hot chocolate or watch a movie!



CF SUPERHERO



Kanan Patel, MS, RD, LD
Nutritionist
CHOA/Scottish Rite

Where did you grow up?

I grew up in India until I was 15 and then moved to Charlotte, North Carolina. I went to UNC-Chapel Hill and then lived in New York City for 8 years before finally settling down in Atlanta.

Who is your family?

I am married and I have two beautiful and loving boys age 4 and 2, who are my world.

How long have you been in the field of CF?

I have been working as a pediatric dietitian since 2001 and had some experience with inpatient CF over the years. However, I have been exclusively working with the CF patients since 2007 at the CF center at Scottish Rite.

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

When I moved to Atlanta in 2007, the CF team nutritionist position was the only available position in pediatrics. Soon after I started, I realized that this is my passion. I love that there is continuity of care. I love that I will know and work with my patients for those first important years of life when nutrition is key. I feel that this is one field where what I do with my patients can really make a difference in their quality of life.

Where did you attend college?

I got my Bachelors of Science in Public Health from University of North Carolina at Chapel Hill and my Masters of Science in Nutrition from Long Island University in New York.

If you could have one superpower what would it be?

Being able to create a super protective shield, mainly because I am afraid of bugs.

What is one thing you miss about being a kid?

Being worry free. I know learning about the world and worrying about everything is part of growing up, but sometimes, just sometimes, it would be nice not to worry about a thing in the world.

Name one word that describes you:

MOTIVATED

What is one accomplishment that you are proud of?

I am not a runner but I have run the Georgia Publix Half marathon three times with the 65 Roses team.

What is one thing that most people do not know about you?

I am a trained vocalist in Classical Indian Music. Although it has been 20 some years since I gave an official concert, I still sing when my family and I get together.

Links of Interest

cff.org

georgia.cff.org

milesforcysticfibrosis.org

reachingoutfoundation.org

choa.org/cf

happyheartfamilies.com

cfvoice.com

cysticlife.org

shamrockinforacure.com

Turkey Rice Dinner

1/2 c. each sliced carrot, sliced mushrooms, and diced onion
2 tsp. butter
1 sm. garlic clove, minced
1 1/2 c. water
2 oz. uncooked instant rice
1 packet instant chicken broth and seasoning mix
1 tsp. browning sauce
1/4 lb. skinned and boned cooked turkey, cubed

In 10-inch nonstick skillet melt butter; add vegetables and garlic and sauté over medium-high heat, stirring frequently, until vegetables are tender, 6 to 8 minutes. Add remaining ingredients except turkey; stir to combine and bring mixture to a boil. Reduce heat to low, cover, and let simmer until rice is tender and flavors blend, about 15 minutes. Add turkey and stir to combine; cook until heated through, about 5 minutes longer.
Makes 2 servings.

Each serving provides: 2 Protein Exchanges; 1 Bread Exchange; 1 1/2 Vegetable Exchanges; 1 Fat Exchange; 5 Optional Calories.
Per serving: 278 calories; 21 g protein; 7 g fat; 32 g carbohydrate; 39 mg calcium; 616 mg sodium; 44 mg cholesterol; 1 g dietary fiber