

CF Connection

**Special
Edition!**

Fall 2007

University of Florida Pediatric Pulmonary Center

Family-Centered...Who Cares?

Family centered care is a phrase being heard more and more in healthcare. It means that medical professionals have come to realize that caregivers and families have a major impact on a patient's continued health and well being, and they cannot be ignored.

In the past, healthcare was focused on the patient only. With the recent realization that the family needs to be considered in the patient's healthcare, many policies are being implemented that favor family involvement.

What does this mean? Two of the main policy areas are safety and quality of care. In many hospitals and institutions around the country, families are consultants to advisory councils. Their input is sought when a new project is undertaken (such as building a new facility) or when trying to improve patient care (such as cutting down on clinic wait time).

The Pediatric Pulmonary Center at the University of Florida is committed to family centered care. Currently, the division employs two part-time family partners, Robin Muetzel and Angela Miney. Our task

is to help the division improve its service to patients and families. We do this in many ways, such as maintaining active and regular contact with patients (especially those recently hospitalized); telling "our stories" to trainees and staff in the division; and participating on community-wide work groups. The PPC wants to respond to the needs of people with CF and their families.

Angela Miney and Robin Muetzel

Special Edition!

This issue of the CF newsletter has been put together *by* people with CF and their families and is *for* people with CF and their families. It includes articles from adults who are living successful and fulfilling lives while managing their CF. There is input from caregivers on the challenges they face and advice they would give other caregivers. If you have any comments about this newsletter, would like to contribute to the next edition, or have any questions about family-centered care, please let us know (contact info on page 6).

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We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 6 or e-mail them to hillajb@peds.ufl.edu.

Thank you to Solvay Pharmaceuticals for funding the printing of this newsletter.

Living with Cystic Fibrosis

Another day, hopping in my truck, loading up my 22-month-old son into his car seat and heading to work. I load my Pulmozyme into my neb machine before starting the truck and head off. I finish my treatment, drop my son off at daycare and head to the office. At times, there is little notice that I have CF or any health condition for that matter. My toddler son knows my treatments as a regular part of our life.

Of course life has not always been this easy. There were times when I was so ill I remained in the hospital for weeks. I had pulmonary bleeds. My stomach wreaks havoc at times. I always seem to get hospitalized around a major holiday or family event.

I was diagnosed with CF as a toddler, after a newborn sibling died of complications of CF. I was fortunate to be reasonably healthy as a child. In late adolescence I became more ill, requiring more hospitalizations. I became familiar with the hospital regimen and the nurses. As an adult, I now realize I do have limitations. I watch my diet, stay away from environments that would irritate my health, get plenty of rest, keep my stress to a minimum and of course, do treatments.

Now turning 46, almost 20 years working for Shands Healthcare, I am the father of three children. My wife and I moved mountains to adopt our youngest son from Guatemala. I have been able to salmon fish in Alaska, snorkel in the Caribbean and trek through Guatemala seeing a completely different world. For any adult, these adventures are great but the day-to-day life of work, being a husband and dad is the adventure that suits me best.

As I pick up my son from daycare I wonder if I will be able to see him graduate from school, see my children get married. I wonder if I will ever be a



grandparent or get to retire from my job. I don't wonder about these things as much as I did a few years ago. My health seems to be in a holding pattern and I am optimistic that I will be able to experience some of those senior years. I imagine I will cherish those senior events and will truly be blessed that my battle with CF did not prevent me experiencing them.

Bill Johnson, age 46

Tailgate 2007

The third annual Tailgate fundraiser at UF's Ben Hill Griffin Stadium on September 22 raised \$57,000 for the Cystic Fibrosis Foundation! This is the highest amount we have ever raised for a CF event in the 9 years we have been doing this. We had a full house! Albert and Alberta stopped by for a visit and 50 members of the UF band joined us for some awesome music. The live auction items brought in thousands of dollars. Our silent auction was a big hit, raising over \$6000!

Contributed by Carrie Godfrey

Living with Cystic Fibrosis

Around 22 years ago, my parents and family were told I had Cystic Fibrosis - and to prepare for the worst. My mother, who was already an active member in the medical community, decided that "the worst" was not an option. With my father behind her, they decided to investigate what medical science had to offer. It is because of their encouragement and belief in me that I am here today.

I'm a 23 year old living with C.F., surviving the disease. I do believe in a higher being, and I believe that I was given this disease to share and educate the world around me, because I can handle "it". There is a reason for everything, and by no means do I look at Cystic Fibrosis as a "punishment". This is not to say that I felt the same way when I was younger.

As a young adult now, I want parents of children with Cystic Fibrosis and patients with C.F. to realize that we are no longer the "statistic." We are living full, active, and healthy lives. I still have the same packed health regimen I did when I was younger, but now I have added more to my plate. I live in Ocala with my boyfriend (who I love cooking for), and I am working on finishing college in December with a degree in Cardiovascular Technology. I plan on getting married, having children, and living in a big house with lots of animals. I also plan on staying as healthy as possible for as long as possible, by pre-planned tune-ups regardless of how many it takes. None of my dreams differ from that of any girl. I just have more things to consider when sorting through the details.

Getting married will be great (hopefully within a year or two)...but I have to make sure I have health insurance where I work and that I am also covered under his plan. Having children will happen for me, just not the traditional way (most likely we'll adopt

for my health). And as for the big house and lots of animals-well, let's just say a girl can dream! Parents and patients need to know one thing before taking on the challenge of living with Cystic Fibrosis...We need to support and educate each other as much as possible. I've received guidance and encouragement from everyone around me; such as Abilities of Florida, great doctors and health care providers to my family and friends. With all this being said, I wish you the best of health and happiness.

Ashley Audet, age 23

Thanks to Our Sponsors!

Many thanks to all the companies that have donated to the Family Advisory Board! We have been giving coupons to our inpatients for great tasting food from outside the hospital and also help parents with additional resources for food.

- GATORFOOD.COM—Meals from Gainesville restaurants for our teenage inpatients
- SONNY'S BBQ—Kids meal coupons
- BLOCKBUSTER VIDEO—One-week movie or game rental coupons
- BURGER KING—Hamburgers and fries coupons
- PIZZA HUT—Personal Pan Pizza coupons
- CICI'S PIZZA—AYCE Buffet coupons
- DOMINO'S PIZZA—Pizza coupons
- OUTBACK STEAKHOUSE—Free burgers on July 4th to our inpatients
- BENNIGAN'S—Kids meal, Book-it coupons
- ON THE BORDER—\$10 coupons
- DOLLAR GENERAL—Christmas donations
- GENENTECH—Provides items for our coupon packs, hand sanitizers, folders and food for our meetings

Robin and Angela

Families Speak Out!

We asked a few people with CF and their families to share their concerns and also some tips for others living with CF. Here are their responses...

What is your biggest challenge at the moment?

Trying to take care of a sick child in the hospital and be there for the ones at home too. I have two children with CF, and they are not always sick at the same time. - Carrie, mom of Megan, age 16 and Jillian, age 13

Getting a job that pays well, staying healthy, and keeping up with my meds and stuff so my parents quit bugging me. - Jake, age 19

Encouraging my son to wear a dust mask when he is mowing yards and also keeping him motivated. - Jerry, dad of Jake, age 19

Getting Katie to gain weight. I also worry about her starting school and how her health will hold up. - Linda, great-grandmom of Katie, age 5

The one and only challenge we are facing right now with JC is once in a while getting him to do his vest; most of the time he is willing do it since he has been doing it for so long. - Angie and John, parents of JC, age 7

Getting Daniel to eat food that is high in calories. He loves fruit and veggies, so I've learned to add high-calorie dips and to cook with butter. And he likes to eat food that he can help cook. - Tina, mom of Daniel, age 5



What is one piece of advice you would give other parents?

Hang in there...it will get better. Things could be a lot worse and just take each day as it comes. - Carrie, mom of Megan, 16 and Jillian, 13

Be strong and keep trying. Having an illness like this that never goes away sometimes gives Jake a reason to "give up" easier. Keep on them to always try new things. If a job or activity doesn't work out, then try another. - Jerry, dad of Jake, age 19

Keep children away from sick people. Katie is starting to fight off some of the colds, but it is better to keep them away even if it's a family member who is sick. - Linda, great-grandmom of Katie, age 5

Don't make a big issue about things. Cystic fibrosis is part of who JC is and that's the way we treat it. He just does it all because he is used to it, and that's how he knows he will stay healthy. - Angie and John, parents of JC, age 7

Don't get in a power struggle about getting your child to take his/her medicine. Try turning it into a game. I tell Daniel that I bet he can't take his meds before I pour my drink, or before someone sits down at the table for dinner. His favorite challenge is when I set out all his pills, and tell him not to take his meds before grandpa gets to the table. - Tina, mom of Daniel, age 5

Keep your kids active in sports or other activities if possible. - Rhonda, mom of Stephanie, age 18 and Jordan, age 15

If you are a parent of a child with CF, please let us know how you keep your kids motivated. If you are a teenager with CF, please let us know how you keep yourself motivated. We'll share your responses in an upcoming edition. This is a great way for families living with CF to communicate with other families!

A Sister's View

My name is Adrienne and I'd like to let parents of children with and without CF know what it is like from the perspective of a sibling (without CF) of a child with CF. When my mother was pregnant with my brother I was more than happy; at that point I was the youngest child and I really wanted someone to be younger than me so I could be the teacher when I wanted to play school. So when my little brother came along, I had big plans for him.

He was a beautiful little blonde-haired, blue-eyed baby and he was seemingly healthy. Problems began when he was 4 months old and became severely dehydrated. I was 8 years old and worried sick; my baby brother that I had such big plans for would no longer even attempt to drink a bottle, and my mom was feeding him with a medicine dropper. We took him to the local ER where they said he probably had a stomach bug and would get over it. Mom didn't accept that answer and took him to another doctor who said it was something more and sent her immediately to Shands where he was diagnosed with CF.

I felt scared, but relieved that we knew for sure what was the matter and what to do for him. We brought him home from the hospital, and the treatments and medications began. It was very time consuming for my mom, and overwhelming for me. But my mom did the best thing she could have done for either of us at that time—she got me involved. She taught me how to perform chest PT, told me how many enzymes to give him at feeding times, and let me do ANYTHING that I was able to do.

So instead of feeling like I was pushed to the sidelines, I felt like I was a part of helping to make him as well as we could. At the same time an unbreakable bond was forming between my brother and me. I was a sister to him, but I also felt like a little mother looking after him. I am 27 years old and my brother is 19 now and there hasn't been one day

since the day he came into my life that I have felt jealous, or like he is the reason

why I haven't gotten to do something I wanted to do. I really believe that getting involved in his care so early on made the biggest impact on me. If I had a friend who was sick I stayed as far away from that person as I could, or if I was sick I would stay with a friend until I was well. I used to joke and say I was being quarantined but the last thing I wanted to do was be responsible for him getting sick.

If I could give any suggestions to parents who are worried about the time they have to spend with their child who is sick, and don't want siblings to feel left out, I would just say to get everyone involved in caring for him/her, not only does it help the child without CF feel like they are a part of everything going on in the family, it also creates a sense of responsibility in keeping their sibling well. I know from first-hand experience that if your other children know everything about their sibling's healthcare needs, they will understand that you are not spending more time with one child versus the other because they are loved any less; they will know that it is just a way of life and they will understand and also know that if situations were reversed that you would do the same for them.

I now have children of my own and I truly believe that being so involved with my brother's care has helped me with the responsibilities and hardships that go along with motherhood. I hope that telling my story can help families of people with CF and I would also like to extend an invitation to anyone who might have any questions for me to feel free to e-mail me anytime at awilson181@yahoo.com.

Best Wishes, Adrienne



Accio Energy Island in the Sun

Recipe by Wendy Abrams
msabrams3018@yahoo.com

This smoothie (not shake...too trendy for that!) takes its name from a Harry Potter summoning spell and the place that its flavors should transport you. It's a smoothie sensation that's packed with nutrients, calories, and fat and is amazingly light! It won't weigh you down, so feel free to dance, workout, play sports, study....whatever! Don't take my word for it...try it! Experiment with other fruit to make your own smoothie sensation, too!

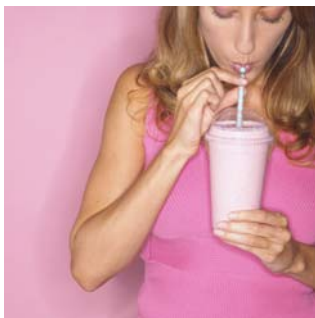


Ingredients:

- ½ cup coconut milk
- ½ cup 2% milk
- a few slices of cantaloupe (or balls)...you adjust the fruitiness!
- 1 packet of Carnation Instant Breakfast (any flavor)
- optional: mix in crushed ice for an additional tropical island feel!

What to do:

Chunk the cantaloupe so the rind is removed if you are using slices. Put ingredients in blender in above order. Blend for a minute or more; it takes awhile for the cantaloupe to blend. Blend for a shorter time if you'd like small bits of fresh fruit. It looks thick, but it has a very light finish!



Nutrition Info:

500 calories
15 g protein
46 g carbohydrate
32 g fat
277 mg calcium

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