

CF Connection

Summer/Fall 2017

University of Florida Pediatric Pulmonary Center

That's Gross! Helping picky eaters try new foods

How can we encourage kids to try new foods? What are things we should do or say when introducing new foods?

Studies show that children may need 10-15 exposures to a new food before they are willing to try it. Don't give up on offering new foods that have been turned down before. While it's hard to do, try not to label your child as "picky." Kids pick up on this and may begin to take pride in their picky eating.

Also, try to set a good example with a healthy attitude toward meals. Don't make a huge deal about food or draw attention to your child's eating. Instead, sincerely compliment him when he does try something new. Including your child in meal planning and cooking can also help him feel more ownership in the meal.

Remember that your "job" at mealtime is to prepare and provide food. It is your child's job to eat. You aren't expected to be a short order cook or immediately give snacks after uneaten meals. It is okay to say something like, "Uh oh, it looks like you didn't eat much of your lunch; I bet dinner will sure taste good to you tonight". Yes, calories are important, but healthy eating habits and a good meal schedule will benefit your child for years to come!

What are some creative ideas to add extra calories to everyday foods? You've probably already heard about adding butter to your kids' meals. Here are some other fun things that can be added to breads, fruits, vegetables, meat, or dairy to add extra calories. Mix it up when you can and try to have fun with it!

- ✓ Nutella
- ✓ Peanut butter (or other nut butter)
- ✓ Cream cheese
- ✓ Ranch dressing
- ✓ Melted or shredded cheese
- ✓ Coconut oil or olive oil
- ✓ Brown sugar
- ✓ Powdered sugar
- ✓ Honey
- ✓ Jam
- ✓ Caramel dip
- ✓ Avocado
- ✓ Walnuts, pecans, or other nuts
- ✓ Breading on meats
- ✓ Bacon
- ✓ Canned French-fried onion rings
- ✓ Heavy cream or half-and-half
- ✓ Mayonnaise
- ✓ Carnation Breakfast Essentials powder

Source: Karen Maguiness is a board certified specialist in pediatric nutrition. She is currently the Dietitian for the Section of Pediatric Pulmonology, Allergy and Sleep Medicine at Riley Hospital for Children, Indiana University Health.

Inside this issue:

Support for Patients and Families	2
Welcome!	3
Fundraising Events	3
Family Corner	4

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 4 or e-mail them to hillajb@peds.ufl.edu.

Support for Patients and Families

People with health conditions (and their parents) often benefit from talking to others in similar situations. The CF Foundation recommends against in-person meetings for people with CF, but a number of online forums are available. You may have found an online group or Facebook page you like, but here are some others to consider.



The UF Pediatric Pulmonary Center holds distance meetings for caregivers of children/teens with CF, via Vidyo, a program like Skype. Its very simple – we send the link and you click on it! Contact Mohammad Zafar (352-273-8380) for more information.

Facebook Pages: There are many CF-related Facebook pages, for which you can search. The groups listed below were developed, and are monitored, by a CF social worker who is also the mother of a child with CF:

<https://www.facebook.com/groups/169426020150446/> (for teens/young adults born from 1996-1997)

<https://www.facebook.com/groups/899636420143114/> (For teens born from 1998-1999)

<https://www.facebook.com/groups/323698677976770/> (For teens born from 2000-2001)

<https://www.facebook.com/groups/899636420143114/#> (For teens born from 2002-2003)

<https://www.facebook.com/groups/1252008408156285/> (For teens who have a sibling with CF)

The Cystic Fibrosis Research Institute (<http://www.cfri.org/home.shtml>) hosts a support group for caregivers of children with CF that can be accessed by phone. These are held on the third Tuesday of the month from 1:30-2:30 pm EST). The call in number is: 1-866-754-2979, Access Code is: 8889479. Check out the CFRI website for lots of other good information.

Attain Health Today offers coaching and mentoring for people with CF <http://attainhealth.today/>

Cystic Life (<https://cysticlife.org/>) is an online group that allows people with CF to communicate with each other and offers other resources.

The CF Foundation (<https://www.cff.org/>) offers “MiniCons” for young adults with CF (18 and over). You can email minicon@cff.org for more information. The CFF website also has lots of good information and videos for people with CF.

Apps for CF Care. These are different from support options, but they can help people with CF manage their care. “Habitica” (<https://habitica.com/static/front>) which may appeal most to patients who enjoy online gaming. It uses positive reinforcement by rewarding players with different types of points/game successes when they complete the tasks/goals/treatments that they have entered in for themselves. It is similar to magical/fantasy games. “Mango” (<https://www.mangohealth.com/>) This app will reward users with things such as Target gift cards or gifts to charities for consistent adherence!

Welcome Sandra Baumstein, PhD

Hi! I'm Sandra Baumstein and I'm the new CF pharmacist. I have already had the pleasure of meeting some of you in clinic and look forward to seeing all of you in the near future. I am available during clinic visits to help you with any medication issues or concerns. In addition, I will also meet with each of you once a year to do a complete review of all of your child's medications. This will help me get to know you and your child better and to be sure all records are up to date. I am also happy to answer any medication questions you may have and help you fix any issues that could interfere with your child's therapy.



Welcome Mohammad Zafar, LCSW

Hi! I'm Mohammad and I'm the new CF Social Worker. I hope to help you and your family in different ways, such as assessing and fulfilling patient and family needs, giving resources and referrals to social service agencies, helping you navigate the complex medical system, and providing crisis intervention and counseling services as needed.



Just a little bit about myself: I am a proud Floridian, born and raised in beautiful Panama City. I am a graduate of both UF and FSU though my true loyalties lie with the garnet and gold...just don't tell my employer! My two favorite things to do are to hike/camp in the Great Smoky Mountains, and snorkel the emerald green waters of Panama City Beach being on the lookout for stingrays. It is my hope for you and your family to receive the best patient-centered care possible. If we can ever be of any assistance, please never hesitate to reach out. We are here to support you, and it is our privilege and honor!

Upcoming Fundraising Events

CF Cycle for Life– Orlando

Date: October 1, 2017 Location: Volusia County Fairgrounds

Get your wheels in motion and join us for our 6th annual bicycle event as we ride through some of the most picturesque and scenic terrain in Seminole and Volusia Counties. CF Cycle for Life is a fully-supported ride with route options of 32, 65 and 100 miles.



Gainesville Tailgate~ Kickoff to a Cure

Date: November 11, 2017 Location: Ben Hill Griffin Stadium, Touchdown Terrace

With various companies, restaurants and families, this Saturday fun will offer guests the opportunity to "tailgate" with foods from local restaurants while cheering on the Florida Gators in their away game against the South Carolina Gamecocks. Their will be TV's airing the game in the Touchdown Terrace, Spurrier Field, and Ben Hill Griffin Stadium. Our live auction will take place during half time, while the silent auction of artwork, sports memorabilia, and getaways will run throughout the day. We hope you will join us for a fun day and a fantastic gator win!



For more information about these and other local events, visit www.cff.org

University of Florida Pediatric Pulmonary Center

Family Corner

We Want Your Feedback!

It seems that everywhere we go these days someone is asking us to fill in a survey or a questionnaire. Do you ever wonder what happens with them? Does anyone ever look at them?

Here at UF Health we are interested in how happy you are with the care and service we provide when you are in the hospital and visiting our clinics.

Inpatient satisfaction surveys - After an inpatient stay, you may receive a survey in the mail about your stay in the hospital. We would really like to hear from you. The hospital does not know who gets the surveys and individual responses are kept private. All responses are put together in one general report. We are interested in how the stay was for you and your child. Did you feel that the doctors, nurses, and other members of the healthcare team listened to you? Did you understand the plan of care for your child, especially when you went home? How was the general environment – was there a lot of noise, was your room and the public areas you were in kept clean?

Outpatient surveys - Asking for your opinion about outpatient clinic experiences is more common now than it used to be. If you have given us an email address, you may get an email asking you to complete an electronic questionnaire. Again, we are particularly interested in how you and the team communicated. We are also interested in how long you spent in the clinic and if we met the particular concerns you had that day.

The hospital has a team of people who go through all the responses and they are particularly interested in the free response comments. We read all your comments and pass them on to appropriate people for action. This is one of the principal ways we get feedback from our patients and families so we want to know the good and the bad! Although it might seem like a lot of work, we really appreciate the time you take to give us feedback. We use your feedback to improve care and make the experience with UF Health better for everyone. Thank you for taking the time to complete our surveys!

Angela Miney, Family Partner
aminey@peds.ufl.edu
352-273-8508

Pediatric Pulmonary Center
University of Florida
Health Science Center
P.O. Box 100296
Gainesville, Florida 32610-0296

Phone: 352-273-8380
Toll Free: 1-800-749-7424
Fax: 352-294-8098

Physicians & Nurse Practitioners:

Michael Light, MD
Silvia Delgado-Villalta, MD
Mutasim Abu-Hasan, MD
Mary H. Wagner, MD
Dima Ezmigna, MD
Sreekala Prabhakaran, MD
Brandon Seay, MD
Trang Bui, MD
Matthew Pertzborn, MD
Dawn Baker, ARNP
Brittany Latimer, ARNP

Nurses:

Chris Mullally, BSN, RN
Alicia Hardy, RN
Tay Gandy, LPN
Ticea Cannon, LPN

Nutritionists:

Ellen Bowser, MS, RN, RD
Jennifer Hillan, MSH, RD, LD/N

Social Workers:

Susan Horky, LCSW
Mohammad Zafar, LCSW

Clinical Psychologist:

David Fedele, PhD

Pharmacist:

Sandra Baumstein, PhD

Respiratory Care:

Shands/UF Pediatric Respiratory
Care Team

Family Partner:

Angela Miney—aminey@peds.ufl.edu

Office Staff:

Brenda Martin
Lisa Harvey