One of the biggest challenges with our CF kids is around food. We all know the importance of keeping up their weight and most of us have probably experienced how hard that can be at times. One of the earliest power struggles for any parent, but especially a CF parent, is around food.

The bottom line is that we can’t make a kid eat! And, of course it makes us parents crazy when our kid with CF won’t eat. So it is very easy to get hooked into a power struggle over food.

Remember: When one demands, the other resists. So the more you try to make your child eat certain foods or a certain amount, the more your child will naturally resist. So, the earlier you start with sharing control around food choices, the better.

And, since I know food is a really big issue for many of us, here’s a few more tips for avoiding food fights:

• Because this is so important, I have to say this again: do not show anger and frustration over food issues. Show encouragement when they eat well and empathy when they don’t. Encouragement sounds like, “Way to go eating up all your food. I’ll bet you feel good about taking such good care of your body.” And empathy sounds like: “Oh, that’s too bad you didn’t eat dinner. I guess you won’t be joining us for that special, yummy dessert I made. Ohh bummer.”

• And along these lines, use dessert and treats as a positive consequence for eating properly. Our kids are not allowed to drink soda pop or eat junk food unless they eat their healthy food first. I was packing my daughter’s lunch recently and had put in an oatmeal cream pie which she just loves. She was dawdling over breakfast and I could see that if she didn’t hurry it up, she’d run out of time. I was so tempted to nag! But instead, I simply took the oatmeal pie out of her lunchbox and set it on the counter. And I said, “Looks like you might not finish your breakfast in time so I’m not sure that you’ll be having this today. But I’ll set it right here just in case you finish.” And you should have seen that little mouth move. And she did it! And, we were both happy about it. I said: “Yayyy Kasey! You get your cream pie!”

• Example- use the power of example. You be excited about trying new foods and eating properly. Say things like “Oooh- I feel so good when I take care of my body!”

• One mom shared how she gets her 4 and 7 year olds to eat all of the kinds of foods everyone else wants to eat but can’t! They get to have brownies and ice cream with hot fudge for dessert but mommy and daddy get grapes.

• And one last point about kids who don’t want to eat: It is important to rule out medically based reasons before just assuming that it’s a behavioral problem. So rule out things like acid reflux, or sinus or lung infections, or if any medications might cause stomach upset or decreased appetite. Be sure to discuss eating challenges with your doctor- good nutrition is so important with CF.

Our kids love that!

And for teens with CF, many parents have had good success with keeping a small refrigerator in their child’s room. They keep it full of the high calorie foods and drinks the teen, and their friends, like. Making it easy and convenient to keep the calories up is a key for this age group.

• And, we really “talk-it-up” how lucky our kids are that they get to eat all of the kinds of foods everyone else wants to eat but can’t! They get to have brownies and ice cream with hot fudge for dessert but mommy and daddy get grapes.

• And one last point about kids who don’t want to eat: It is important to rule out medically based reasons before just assuming that it’s a behavioral problem. So rule out things like acid reflux, or sinus or lung infections, or if any medications might cause stomach upset or decreased appetite. Be sure to discuss eating challenges with your doctor- good nutrition is so important with CF.

Lisa Greene
www.happyheartfamilies.com

Author: Parenting Children With Health Issues
March 4, 2010. A new inhaled antibiotic for the treatment of cystic fibrosis called Cayston is now available for patients through select specialty pharmacies, including the CF Services Pharmacy. Cayston is the first CF drug to advance from beginning to end through the Cystic Fibrosis Foundation’s Therapeutics Development Program.

Cayston, formally known as AZLI, is for the treatment of Pseudomonas aeruginosa. It was approved by the U.S. Food and Drug Administration last week.

Cayston is administered with a new device called the Altera Nebulizer System that allows patients to take the medicine in less than five minutes, a fraction of the time required for other inhaled antibiotics. It is the first new inhaled antibiotic developed for CF in more than a decade.

To support CF patients, Gilead Sciences, Inc., maker of Cayston, is launching a Cayston Access Program, a call center established with a nonprofit subsidiary of the Cystic Fibrosis Foundation. The program helps people with CF and members of their care team with insurance verification, co-pay assistance and claims support. For information, visit www.cayston.com, or call 1-877-7CAYSTON (877-722-9786).

For most patients with private insurance, the prescription cost will be limited to a co-pay of $25, as a result of Gilead’s support. If you do not have insurance, Gilead has a special program that offers Cayston free to individuals with CF who meet the eligibility criteria. To learn more, call the Cayston Access Program.

Please Welcome the Newest Addition to the Cook Children’s CF Team: Jamie Cole, LCSW

We are excited to welcome, Jamie Cole, the new social worker to the Cook Children’s CF Clinic. Jamie can assist CF patients and their families in the following areas:

- Provides information and referrals to appropriate community services.
- Provides patients with information on available scholarships.
- Provides information related to Medicaid, CHIP, SSI, CSHCN (Children with Special Healthcare Needs) Medicare, and Insurance.
- Assists with Patient Assistance Programs for medication costs.
- Inter-agency collaboration (where can we get supplies/equipment if the family has no money).
- Emotional support, counseling, and problem solving (be available for the families if they need support or problem solving).
- Sees patients and families in the clinic and in the hospital.
- Provides Make A Wish information for families.
Choosing to Live to the Fullest

Spotlight on Katelyn Harlow, a 24 year graduate student with CF.

My name is Katelyn Harlow and I’m a 24 year old graduate student at a private university in central Texas. I was diagnosed with Cystic Fibrosis [CF] at 6 weeks of age and was hospitalized on a consistent basis until I was 24 months old. There are so many facets to having CF that it seems almost impossible to put them all on paper.

I grew up as normal as any other child in my neighborhood. My friends and I would ride bikes and play in the lake near my house. In high school, I hiked the Rocky Mountains with my church youth group and I butchere Spanish while building houses in Mexico. It wasn’t until I was a sophomore in college that I experienced CF in all of its glory. I was busy pledging a sorority and before I knew it, my lung function dipped, along with my weight, and I ended up with my first PICC line in 18 years.

Coping with CF is different for each person – some act out, some embrace, and some just try to make it through each day. It was when I was doing my undergraduate course work that I fully began to embrace this disease. I began to understand the harsh realities of negligence and the joyous benefits of compliance. I realized that in order for me to be ‘normal’, I had to be completely abnormal in how I conduct daily life.

Balancing a full time job, graduate school, and a social life has really taught me how to multi-task and how to be creative. I now do cardio exercises while I do my masks so I can keep my thighs and my lungs happy. I learned how to hack into a computer system so I could do research in my room while I did my treatments when I studied abroad for a semester in England. I put guys to shame when we go out to eat because I can usually eat as much, if not more, than they can.

Despite my attitude towards CF, I’m not immune to it. I break down from exhaustion and I would sometimes rather have a horrendous stomach ache than do my treatments. I force food in my mouth when I have no appetite because I know how important calories are to my health; however, I look forward to what’s coming in life. I look forward to marriage and having children. I look forward to graduation.

I refuse to sit passively and allow CF to have dominion over my life. I choose to live life to the very fullest. Despite how others may perceive me, I have been blessed with the health I have and I plan to use it to its fullest. I may have Cystic Fibrosis, but it certainly does not have me.

The Cook’s Corner: Recipe for Success

Enjoy this tasty treat to celebrate the new season of spring!

EDIBLE BIRD’S NEST BITES

12 oz. bag chocolate chips
1/3 c. peanut butter
3 c. chow mein noodles
1 1/2 c. Rice Krispies

Extras: Jelly Beans, candy coated chocolate eggs, marshmallow chicks

Pour chips into 4 cup measuring cup. Microwave for 1 1/2 minutes. Stir to make sure all is melted. Stir in peanut butter. Microwave 1 to 2 minutes. Stir in noodles and cereal. Cover cookie sheet with waxed paper. Drop spoonfuls of Bird’s Nests on waxed paper. Let cool in refrigerator. Using peanut butter as an adhesive, “glue” down the jelly beans and candy coated chocolate eggs inside the nest cavity. “Glue” the marshmallow chick on the edge or inside the nest. Kids will have a great time making this edible sweet treat. Happy Spring!
Call for New Committee Members!
Join the CCCFFAC Team

The Cook Children’s Cystic Fibrosis Family Advisory Council (CCCFFAC) is now accepting applications for new committee members. Each committee member will be committed to accepting a two year term on the council as well as attend monthly meetings on the second Thursday of the month.

Jamie Cole, CF social worker, will be receiving the completed applications. Applications are available at the CF office or can be requested by email: jamiecole@cookchildrens.org.

Please refer any questions to Jamie Cole.

An online store for cystic fibrosis gifts, t-shirts, stickers, and more!

www.shop.cafepress.com/cystic-fibrosis
Join Us... Great Strides 2010

In cities all across the United States, tens of thousands of people are showing their commitment to “add tomorrows every day” to the lives of those with cystic fibrosis through the simple act of walking.

Year after year, volunteers make every GREAT STRIDES walk site both fun and successful. Their dedication has helped GREAT STRIDES become one of the country’s most effective and efficient fundraising efforts. Since the first GREAT STRIDES walk in 1989, more than $180 million has been raised to support the vital research and care programs of the Cystic Fibrosis Foundation.

With the progression of various medications down the drug pipeline and the significant improvements of quality of care, we need YOUR help to reach the 2010 national fundraising goal by participating in a GREAT STRIDES walk near you. The nearest GREAT STRIDES walk sites include:

- Arlington/Ft. Worth - Six Flags Over Texas: June 13, 2010, 8:00 am
- Granbury - Granbury City Park: May 15, 2010, 8:00 am

Your local CF Foundation Chapter has many skilled personnel who can help assist in your fundraising efforts:

Northeast Texas Chapter - Fort Worth Office
Phone: 817-249-7744
Email: ftworth-ne-texas@cff.org

Here are some great fundraising ideas for GREAT STRIDES:

- Letter writing/Email writing campaign
- Percentage of the Proceeds...
- Garage sale
- Pizza Lunches
- Bake sale
- Ice Cream Social
- Corporate sponsors
- Jeans for Genes
- Collections

Please visit www.cff.org/Great_Strides for additional information

KnowCF partners with www.cysticfibrosis.com to bring CF patients and caregivers featured videos focusing on various CF topics of interest. The most updated video is entitled: A Conversation on Filing Taxes with Cystic Fibrosis. Three of the e-Patient members, Lauren, Victoria and Julie have organized information on CF healthcare costs and tax deductions. These Health Opinion Leaders (HOLs) explain which expenses qualify for deduction and how to track expenses. They have created roughly fifteen minutes of engaging and polished footage on this very valuable topic.

www.cysticfibrosis.com/knowcf
PICC/Port Line Protector

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Exclusive Features:
• Safely allows patients with PICC lines or Port lines to resume normal bathing, showering and approved recreation routines
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Are You Creative???

Do you enjoy drawing, painting, writing poetry, or photography? WE NEED YOUR CREATIVE EXPRESSION!

The Cook Children’s CF Family Advisory Council would like to highlight YOU or YOUR CHILD’S pieces of creative art in our quarterly newsletter!

Please submit all pieces to Carrie Stradley at carriestradley@cookchildrens.org
Come and enjoy lunch, stop by exhibitor booths, and listen to some of our lead staff discuss various topics of interest as related to our patients with CF. Featured presentations include:

1. What’s Current in CF Research and Care

2. Pediatric to Adult Care Transition (PACT)

3. Living a Successful Life with CF: How the Law Can Help

Pick up a CFIT schedule from your CF clinic today.

Save the Date! Cystic Fibrosis Information Time (CFIT)

April 24, 2010
9:30 am-2:30 pm
Children’s Medical Center Dallas
Ambulatory Care Pavilion
2350 Stemmons Fwy
Dallas, TX.