COOK CHILDREN'S CYSTIC FIBROSIS CENTER

Cook Children's Cystic Fibrosis Newsletter

SPRING 2014

IN THIS ISSUE

Surviving Spring Allergies

by Cystic Life

Everyone knows: April showers bring May flowers. What do flowers bring? Pollen and lots of it. Spring can wreak havoc on kids (and adults) who suffer from allergies. Here are some tips for surviving allergy season:

Know the Pollen Count

You can check the pollen count near you through the National Allergy Bureau. Pollen counts calculate a specific kind of pollen in a specific amount of air over a given period of time, such as 24 hours, according to the Asthma and Allergy Foundation of America.

Ask your allergist what your child is allergic to and when that particular pollen peaks, so you know when to take action.

Plan Outdoor Time Wisely

While it's best to avoid the outdoors during high pollen counts, that's not always practical (or fun) for kids. If you can't avoid the outdoors, plan your child's outdoor time carefully.

"Most plants pollinate from 5 a.m. to 9 a.m., says Miguel P. Wolbert, MD, an allergist in Evansville, Ind. Wolbert is certified in pollen counting for the National Allergy Bureau.

Because of this, it is best for your kids to avoid early mornings outside. Additionally, it's better to be outside on calm days than windy days as windy days stir pollen around

Keep Pollen Outside

Keep pollen outside by keeping your windows and doors closed during high pollen count times. Additionally, have everyone who was playing outside change clothes and shower after coming inside. This will prevent pollen from being brought in and around the house.

Take Allergy Medicines

Talk to your child's doctor to see if allergy medicines are right for your child. If your child is prescribed medicines, be sure to ask when and how to use them to benefit your child most.

Improving Infant Nutrition

by Staci Brummet, RD

As part of our ongoing efforts to optimize nutrition and lung function at Cook Children's CF Center, we are excited to announce that we will be expanding our nutrition classification to the newest members of our CF family – our babies under 2 years old.

Why is good nutrition important?

We know that good nutrition is important for people with CF because of the strong association between weight-for-length (in infants/toddlers) or Body mass index (in children/adults) and good lung function.

What is our goal?

Along with the Cystic Fibrosis Foundation, our goal is for all children with CF to reach and maintain a weight-for-length (W/L) at or above the 50th%ile by 2 years of age.

How do we plan to reach this goal?

- **Step 1:** A consult with the dietitian will become a standard part of your child's regularly scheduled visits to the clinic at diagnosis, first follow-up, 2 months, 4 months, 6 months, 10 months, 12 months, 18 months, and 24 months of age.
- **Step 2:** A dietitian will classify your child's level of nutritional risk at every clinic visit. This classification may prompt more frequent visits to the clinic.

- **Optimal**
  W/L≥ 50th%ile, Weight > 10th%ile, *and* age appropriate weight gain
- **Acceptable**
  W/L 25-49th%ile, Weight > 10th%ile, *and* age appropriate weight gain
- **Concerning**
  Slow weight gain or weight loss
- **At Nutrition Risk**
  W/L10-24th%ile *or* Weight 5-10th%ile
- **Nutrition Failure**
  W/L < 10th%ile *or* Weight < 5th%ile

PARTIAL INDEPENDENT VISITS

Please contact the CF coordinators if you have any questions or concerns related to this program.

As a part of our transition program, we are implementing partial independent visits for our patients who are 15 years and older. This important part of the transition program will enable your adolescent to develop the skills and confidence they need to succeed. During your child's 14 year old visits you will be reminded of upcoming partial independent visits. Before your adolescent's first partial independent visit, you will receive a phone call from a staff member to remind you and answer any questions.

When you arrive for your visit, the adolescent will be called back alone to the exam room while the parent or guardian waits in the waiting area. The nurse will review medication list and current symptoms. After PFTs the parent or guardian will be asked to join their adolescent in the exam room. The nurse will then review the health history with both parent and adolescent.

This process will allow your adolescent to become more familiar with their medications, speaking with medical staff, and voicing their health concerns. It will also encourage them take a more active role in medical care. Please contact the clinic with any questions you have.

Cook's Corner: Recipe for Success

No Bake Peanut Butter Bars

For other great CF high-calorie recipes check out: *www.chef4cf.com*

Winning Recipe!

Ingredients

3 cups old-fashioned oats

1 1/2 cups honey

2 (16 ounce) jars of natural peanut butter

1 cup dried fruit (raisins, cranberries, etc)

1 cup crushed nuts (almonds, cashews, etc)

1 tablespoon salt

Directions

1. Combine honey and peanut butter in a large mixing bowl.
2. Combine oats, dried fruit and nuts in a large mixing bowl.
3. Combine dry ingredients with the wet ingredients, one cup at a time, until thoroughly mixed.
4. Press into a 9x9 pan or dish of some kind. Eat right away or refrigerate overnight to let it set.

Serving Size

Serving Size: 16 servings

570 calories per serving

Fat: 32 g

Sodium: 650 mg

Protein: 16 g

CF patient spotlight: Jackson Wynn

by Amy Wynn, mother

Jackson is a vibrant, energetic, four year old lover of Transformers, trains, space shuttles and airplanes. He has been a patient at Cook Children's since he was diagnosed with Cystic Fibrosis at just 19 days old. He loves to sing and play with his sister, Emily. Jackson is the happiest when he can play outside and climb.

We always joke to friends and family that we are married to Cook Children's. Not only has Jackson been a patient since his diagnosis, but his daddy works downstairs in the ER! This means even more familiar faces when he has to stay inpatient.

PARENT UPDATE MEETING

November parent update meeting

Were you unable to join us for the Cystic Fibrosis Patient and Parent Update Meeting in November? If not you can click the link below and watch a recording of the meeting. The meeting served as an update from the National Cystic Fibrosis Foundation Conference

http://av.cookchildrens.org/media/cf111813

GREAT STRIDES 2014

62 teams registered

ARE YOU REGISTERED FOR GREAT STRIDES?

$493,000

This is the goal for Fort Worth/Arlington Great Strides

FOR MORE INFORMATION

May 18, 2014

Check in: 8:00 am, walk: 9:00 am

Distance: 5k

Chapter: Northeast Texas- Fort Worth

SIX FLAGS OVER TEXAS
Arlington, TX

Cook Children's Camp Kindred

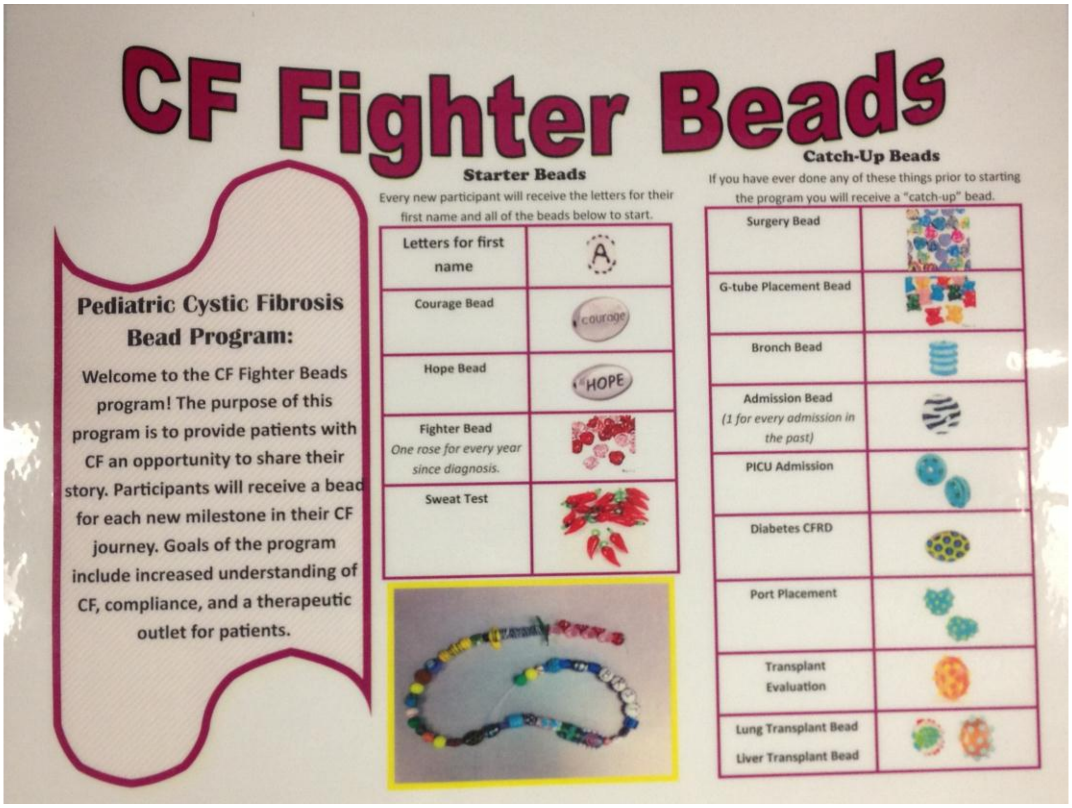
by Alex Steward, CLS

Cystic fibrosis can affect individual patients in a variety of ways but it is no secret that every member of the family is greatly impacted. This April our CF center will join the CF center at Dell Children's to offer a special 2 night weekend camp for children that have an immediate family member with cystic fibrosis. Camp Kindred will be held April 11-13, 2014 at Camp John Marc in Meridian, TX. Through Cook Children's 'Camp for Kids' program we are happy to announce that this weekend is completely free of charge! We will provide transportation from the hospital to camp, all meals, activities, and trained counselors for the weekend. Activities at Camp John Marc are designed to build confidence in children and provide an opportunity to have new life experiences. These activities include: ropes course, star gazing, cooking, arts and crafts, fishing, archery, sports, and nature activities.

Part of the focus of this weekend is to provide a safe place for children to express and share their own personal experiences about having a family member with CF. Our focus will be on the sibling or son/daughter, and not the medical experience of the family member with CF. Most of the weekend will be spent having fun, playing outside, and just being kids, but campers will have the option to attend a short session specifically focused on emotional expression. Please note that this camp is for those related to someone with CF, not CF patients themselves. The mission of Camp Kindred is for siblings of children with CF and children of adults with CF served by Cook Children's and Dell Children's. Children ages 7 (by camp start date) and older are welcome to attend.

If you're interested in a child in your life attending camp in the future, please contact child life specialist Alex Steward at 682-885-4892 or alex.steward@cookchildrens.org

Introducing... the CF Fighter Beads Program



CF Fighter Beads

Pediatric Cystic Fibrosis Bead Program:

Welcome to the CF Fighter Beads program! The purpose of this program is to provide patients with CF an opportunity to share their story. Participants will receive a bead for each new milestone in their CF journey. Goals of the program include increased understanding of CF, compliance, and a therapeutic outlet for patients.

Starter Beads

Every new participant will receive the letters for their first name and all of the beads below to start.

Letters for first name	
Courage Bead	
Hope Bead	
Fighter Bead *One rose for every year since diagnosis.*	
Sweat Test	

Catch-Up Beads

If you have ever done any of these things prior to starting the program you will receive a "catch-up" bead.

Surgery Bead	
G-tube Placement Bead	
Bronch Bead	
Admission Bead *(1 for every admission in the past)*	
PICU Admission	
Diabetes CFRD	
Port Placement	
Transplant Evaluation	
Lung Transplant Bead Liver Transplant Bead	

As caregivers you know better than anyone how hard our patients "fight" to stay healthy and strong!

From daily breathing treatments, doctor appointments, enzymes, and so much more. We wanted to find a way to help our patients share their story and recognize new milestones in their CF care. Thus the CF Fighter Beads program was born!

Starting at age six patients will have the opportunity to participate in the program, individuals who are older than this are welcome to start the program at any time. Patients can "earn" beads for a variety of milestones and experiences including but not limited to: quarterly visits, surgery, lab draws, PFTs, admissions, achieving weight gain goals, and specific transitions.

Once started on the program patients will be responsible for keeping track of what beads they have earned and can collect earned beads at next clinic visit or during inpatient stays. We currently have about 30 patients participating and are looking forward to adding many more! "CF Fighter Beads" is unique to our CF center at Cook Children's although other centers have similar programs.

If your child is interested in participating in the CF Fighter Beads program please contact child life specialist Alex Steward at your next clinic visit!

Cook Children's Staff Bios:

Kristi Tucker, RN, BSN

Kristi is the Adult CF program nurse and also manages our Newborn Screening program. She has worked at Cook's since 2008 and joined the CF Center last July.

Kristi is married and has two boys, ages 2 and 6, which keep her very busy. She is also going to school to get her FNP degree (family nurse practitioner). She enjoys going to t-ball games with her son, taking road trips, spending time with friends, and watching movies with her family.

Cook Children's Retail Pharmacy

Cook Children's PHARMACY

This November, Cook Children's unveiled its very own retail pharmacy. This new, full-service pharmacy offers our patients a convenient option to meet their pharmacy needs.

Some of the services offered at our pharmacy include: online refills, same-day prescription filling for most medications, kid-friendly flavors for liquid medications, text messaging alerts and mail service, and a medication assistance program for those who qualify. In addition, if your child gets a prescription for medicine during their hospital stay, it can be filled at Cook Children's Pharmacy and delivered right to your child's room upon request.

Of course, we realize our CF patients have unique needs. So will Cook Children's Pharmacy carry all of your child's medications? If you have questions about specific medications, contact your CF clinic pharmacist to find out. Just call 682-885-6299 ext.2672.

Name: Cook Children's Pharmacy

Location: Conveniently located on the first floor of the medical center (next to the Emergency Department)

Hours: [8am to midnight, Mon-Fri] [10am to midnight, Sat-Sun]

FOR MORE INFORMATION

Phone: 682-885-3142

Fax: 682-885-6916

www.cookchildrens.org/pharmacy

Cystic Fibrosis Information Time (CFIT)

CFIT is a collaborative partnership between the CF clinics of Cook Children's Medical Center and Children's Medical Center of Dallas. CF parents, patients, and caregivers will have the opportunity to hear various topics of discussion as related to Cystic Fibrosis. Vendors will also be available as well as lunch and break-out sessions.

8:30-9:00a	Breakfast and Vendors
9:00	Brief Introduction
9:10	Pseudomonas Infections (Carolyn Cannon) include Q& A
9:50	Infection Control Guidelines (Michael Sebert) include Q&A
10:30	Break & Vendors
10:50	Healthy High Calorie Eating (Karyn Shaw) include Q&A
11:30	CFRD Primer (Shamita Trivedi) include Q&A
12:10	Lunch & Vendors
1:00	TDN Update (Raksha Jain) include Q&A
1:40	Bench Research Updates (Phil Thomas) include Q&A
2:20	Transition Roundtable (Raksha Jain, David Finklea, Preeti Sharma & Meg Sathe)
3:00	Adjourn

CFIT

April 26, 2014

9:00-3:00 (8:30 breakfast)

2350 Stemmons Fwy Dallas, TX 75235

Independence Hall (outpatient building)

Web Streaming

There will be information available about web streaming which can accommodate up to 100 people online and will be offered on a first come first serve basis. There is not translation services available for webstreaming. To get a login for webstreaming, please contact: Jamie.becker@childrens.com

CookChildren's

The Cystic Fibrosis Center at Cook Children's Medical Center is one of more than 115 accredited CF centers throughout the nation. These centers are accredited by the Cystic Fibrosis Foundation, a non-profit organization founded in 1955 dedicated to funding research to find a cure for CF and improving the quality of life for people with the disease

Pediatric CF Center Staff:

Center Physicians:

- James Cunningham, MD– Co-Center Director (Nurse: Stacy),
- Nancy Dambro, MD– Co-Center Director (Nurse: Jennifer & Karen),
- Maynard Dyson, MD (Nurse: Stacy),
- Sami Hadeed, MD (Nurse: Sharon),
- John Pfaff, MD (Nurse: Jessica),
- Karen Schultz, MD (Nurse: Paulette),
- Shailendra Das, DO (Nurse: Lisa)

Adult CF Center Staff:

Center Physicians:

- John Burk, MD– Co-Adult Center Director,
- Steve Davis, MD– Co-Adult Center Director,
- Stuart McDonald, MD,
- Cyndy Roger, ACNP-BC **(**Nurse: Kristi, adult nurse and newborn screening)

CF Coordinators:

- Janet Garbarz, Carrie Stradley 682-885-6299

Dietitians:

- Staci Brummett, Julie Dubois 682-885-7496

Respiratory Therapists:

- Deanna Pinckney, Alex Rasmussen, Crystal Thompson, Cindy Corne, Shonda Thompson 682-885-4189

Child Life Specialist:

- Alex Steward 682-885-4892

Social Services

- Amy Wilson 682-885-3991

Cook Children's Medical Center and Cystic Fibrosis Center

Pulmonary Services:
1500 Cooper St
Fort Worth, TX 76014-2724

Phone: 682-885-6299

Fax: 682-885-1090

Email: www.cookchildrens.org

Making CF stand for "Cure Found"