

COOK CHILDREN'S CYSTIC FIBROSIS NEWS

VOLUME IX

WINTER 2013

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.

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Our New Transition Program!

On the Move at Cook Children's CF Center

You may have noticed a change to your child's annual evaluation visit. As part of our ongoing commitment to improving care, we have recently started a new education and transition program for patients and families. The goal of this program is to help you prepare your child to successfully manage his/her own health-care. This focused education begins at your child's first visit to the pediatric CF Center at Cook Children's and continues through his/her transfer to the adult program.

We've developed a general timeline of what to expect as your child transitions into adulthood and we look forward to sharing it with you. Remember, transition is a process not an event. It is NOT just a "transfer" to the adult physician. There are many steps involved, and we will work with you and your family to make a plan for as smooth a transition as possible. We are excited about this new program and have already received positive feedback from many families. Please do hesitate to ask the CF team for more information.

Transition:
Preparing to Move to the
Adult CF Program



Cook Children's CF Center



Cystic Fibrosis Lifestyle Foundation

Brian Callanan, a 36-year-old with CF, knows first hand how CF takes a physical, psychological and social toll. He states how it intrudes on his daily life, causes feelings of isolation, and creates a financial strain—all of which can lead to non-adherence to CF treatments. He found that financial and personal support can provide incentive and motivation for the development of an active and healthy lifestyle, which is why he started the Cystic Fibrosis Lifestyle Foundation (CFLF). The CFLF is a non-profit organization that provides financial support to people with CF for recreational activities. It focuses on patient education—specifically the psychosocial challenges of living with CF on a daily basis and how those challenges can lead to non-adherence with medications and treatments. It educates people with CF on the importance of a positive attitude and healthy lifestyle and helps them afford recreational activities. People with CF can apply for a grant at www.CFLF.org.



Breanna Schroeder, left, 2012 grant recipient, and her "Peer Support" dive into better health by having fun.

HomeLine Newsletter Fall 2012

Mark Your Calendar!

What: CF Patient and Family Update

Where: Hochberger Auditorium

When: Monday, February 25, 2013

Time: 7-8:30pm

Equine Programs for CF Patients

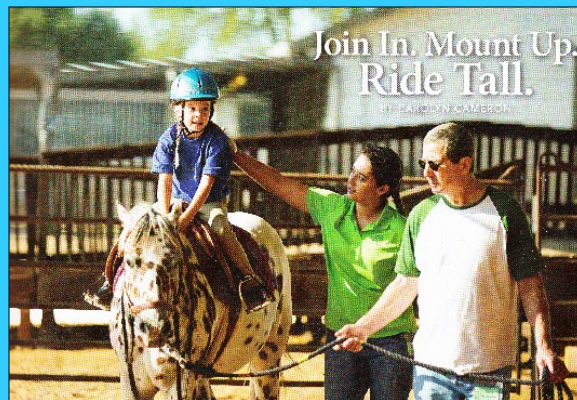
At ManeGait Therapeutic Horsemanship, located on 14 acres in Collin County, children with disabilities including those with Cystic Fibrosis are eligible for the program. Therapeutic Riding lessons are equestrian skill-based lessons for children and adults with disabilities. The focus of the lessons is skill development and progression while improving the rider's physical, cognitive, emotional and/or social skills. Helping the rider reach their full potential is of paramount importance. Taught by a certified therapeutic riding instructor, and assisted by volunteer aids, the lessons offered are group, semi-private or private and are 45 minutes to 1 hour long. As much as possible, the riders participate in pre-mounted and post-mounted horse care. Riders that have physical, intellectual, cognitive, developmental, and learning differences can benefit from Therapeutic Riding. Benefits of therapeutic riding can include improvements in the following areas:

- Balance
- Muscle strength
- Physical endurance
- Range of motion
- Circulation
- Respiration
- Sensorimotor integration
- Help to activate weak brain areas
- Confidence
- Motivation
- Human Animal bonding skills
- Social skills
- Responsiveness and adaptability
- Flexibility


Please see the following sites for more information:

www.manegait.org

www.pawsforreflectionranch.org




After being diagnosed with cystic fibrosis, Kendall Bogley finds relief through therapeutic riding at Manegait Therapeutic Horsemanship. Read the full story at FriscoStyle.com (September 2012)



Meet Apples, the world's greatest physical therapist

You may not know it, but in many ways, the horse is the ultimate physical therapist. By moving the rider's body in a manner similar to a human gait, therapeutic horseback riding helps children and adults with a wide range of disabilities gain strength, confidence and a sense of belonging.

Delivering the best in equine therapy on a beautiful 14-acre site in Collin County, ManeGait brings help and hope to those who need it most.




Cook CF Patient Spotlight!

Tyler Roye

1. Tell us a little about yourself...

My name is Tyler Roye. I am 12 years old and am going into the 7th grade at Loflin Middle School. My favorite sport is baseball. I like to read and go out with my friends.

2. When were you diagnosed with CF?

When I was days old.

3. What are some of your favorite hobbies/activities?

Baseball, basketball, soccer, reading, swimming, taking vacations.

4. What are some of your favorite foods?

Corn dogs, hot dogs, homemade grilled cheese, baked potatoes, and peas.



5. How do you balance life with CF?

I just do my treatments and take my medicine and do what I can to stay healthy. I work out with my Father...

6. Tell us something unique about yourself?

I have been to three countries other than the US – Mexico, Grand Cayman, and Jamaica.

7. What are your future goals?

I want to be a major League baseball player or a doctor or scientist to help find cures for deadly diseases, and common every day illnesses.

8. What's a piece of advice that you might give to someone else with CF?

Keep doing what your good at and push yourself to your limit, and even though you have CF, just like me, you can do it, just like me!

9. How long have you been a patient at Cook CF Clinic?

Since I was born, my whole life.

10. What do you like best about Cook?

The staff and the new building...



Your Child's Medical Record Portal

Access your child's health care information when you need it through mycookchildrens.org

The service is free and can be accessed from your computer whenever you need it. This secure, confidential system allows you to communicate with your child's physician's office about non-urgent medical matters.

Any Cook Children's patient may take advantage of these convenient features:

- View and request appointments
- See test results, based on doctor discretion
- Look at your child's health information
- View and pay bills for Cook Children's Physician Network securely
- Email messages with your child's doctor's office
- Print your child's vaccine record for school or camp
- Receive email and or phone notifications of office closures because of weather



Did you know Cook Children's Medical Center is on Facebook? Click to **LIKE us so that you may receive updates from Cook Children's Health Care System in your Facebook newsfeed.**

Welcome!

Alex Steward, MS, CCLS

I am originally from Snellville, Georgia just north of Atlanta. It has been my dream to work as a Child Life Specialist at Cook Children's since working with the hospital at Camp John Marc during the summer of 2009. I received my Bachelors in Psychology and Masters in Child and Family Development with a Child Life emphasis from the University of Georgia. I completed my Child Life internship at Cincinnati Children's Hospital and became certified in 2011. In my spare time I enjoy reading and watching Georgia football. I am eagerly looking forward to getting to know and working with you and your family in the pulmonary clinic!



Attention Android Users!



The CF-Notebook app for Android is designed to assist people with Cystic Fibrosis in managing their care. CF-Notebook provides a single

place to keep track of all the CF related needs; Meds, Meals/Snacks, Exercise, ACT, Blood Sugars, Appts, Contacts, Refills and Weight. If you have any questions or suggestions after using the app, please email me at OceanVectorDesign@gmail.com

Appointments	
Dr James	8/13/12
CF clinic	9 am
Dr Mary Black-diabetes	8/24/2012
St Mary's	10am

CookChildren's

Cook Children's Medical Center Cystic Fibrosis Center

Pulmonary Services
1500 Cooper Street
Ft. Worth, Texas 76104-2724
Phone: 682-885-6299
Fax: 682-885-1090
Email: www.cookchildrens.org

Making CF stand for "Cure Found"

Pediatric CF Center Staff:

Center Physicians: **James Cunningham, MD**– Center Director (Nurse: Stacy), **Nancy Dambro, MD**– 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**– Adult Center Director, **Steve Davis, MD**, **Stuart McDonald, MD**, **Cyndy Roger, ACNP-BC** (Nurse: Sofia, adult nurse and newborn screening)

CF Coordinators:

Janet Garbarz, Carrie Stradley 682-885-6299 (#6)

Dietitians:

Staci Brummett, Cristina Puga,
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 682-885-2863

Cook's Corner: Recipe for Success

Bacon Mushroom Chicken

Ingredients

- 2– 4oz. Chicken breasts
- 3 Tbsp. Melted butter
- 1 garlic clove minced.
- 4 thick slices of bacon
- 1/2 c. sliced mushrooms
- 1/3 c. heavy cream
- 1/4 c. cheddar cheese

Directions

1. Preheat oven to 350 degrees.
2. Place melted butter and garlic in 9 x 13 pan. Place chicken in pan, top with bacon and mushrooms. Bake for 45 minutes or until no longer pink. Put cheese on top and bake 5 more minutes.
3. Remove chicken and place on platter. Pour juices from pan into small saucepan. Whisk juices with cream over low heat until thickened.
4. Pour sauce over chicken and serve warm.



Nutritional Information per chicken breast: 153 mg calcium, 72 g fat, 30 g protein, 824 calories, 813mg sodium