

October 2013

The CF



Breeze

“Wisdom & inspiration for CF families”

Exercise Can Be Fun

It's never to late to start...

The goal with Cystic Fibrosis and Physical Therapy (PT) is to focus on prevention, education, and treatment of areas of complication. Making families aware of complications and teaching exercises in five basic areas: breathing, rib cage mobility, bone density/leg strength, core strength and endurance may help with preventing complications with the body structure.

The benefits of exercise can include enhanced mucus clearance, improved muscle strength, improved endurance of respiratory muscles, improved self esteem/body image/quality of life, increased bone density, enhanced immune function, weight gain/fat free mass, increased work capacity, beneficial effects on FEV1 and FVC and predictor of survival.

Exercise does not have to be a structured routine your child does daily. It can start early on as an infant by how you play with your child. Encouraging your child to maintain an active lifestyle may include being a good role model by including exercise in your life. Being active from the beginning is important, but it is never too late to start. Here are a few age appropriate handout for your family to make things fun and easy.

[Infants](#) [Ages 1-3](#) [Ages 4-6](#) [Ages 7-12](#) [Age 13+](#)

If you have questions you can contact Children's PT Department, Julie Christiansen at 612-813-6376 or e-mail julie.christiansen@childrensmn.org

Upcoming Events

October 28- CF Parent Support Meeting
Children's Minneapolis

November 2 – CF Education Conference
The Commons Hotel, Minneapolis

November 16 – Mortenson Construction
Breath of Life Gala
Hyatt Regency, Minneapolis

November 25- CF Parent Support Meeting
Children's Minneapolis

January 27 - CF Parent Support Meeting
Children's Minneapolis

For more information, visit:
www.cff.org/Chapters/minnesota

The CF Breeze will be distributed electronically for patients and families of Children's Hospital and CRCCS.

To be added to the distribution list or to update your e-mail address, please complete a listserv form available in the lobby of CRCCS or by contacting Mary Sachs or Sandy Landvik.

Hospital Visitor Guidelines Now in Effect

To help reduce the spread of winter cold and flu viruses, Children's strongly encourages families to limit the people coming along to your outpatient or emergency department visit to just the parent and ill child if possible.

If your child is admitted to the hospital, the following seasonal visitor guidelines will apply:

- Parents are welcome to visit at all times and are not considered visitors.
- All parents and visitors must be screened for wellness each day.
- Visitors, including siblings, may not visit if they have a fever, cough, sore throat or runny nose.
- Visitors, including siblings, must be age 5 years or older.
- Visitors are limited to four people at a time. This includes parents, siblings and other visitors.
- Parents or visitors may be asked to wear a mask while in the hospital.

Thank you for your understanding and cooperation to help us protect our patients, families, staff and visitors. If you have any questions about our visitor guidelines, please ask a member of Children's staff.



TOBI[®] Podhaler[™] now available

tobramycin inhalation powder

TOBI Podhaler is a prescription medicine used to treat people with cystic fibrosis who have a bacterial infection called *Pseudomonas aeruginosa*. TOBI Podhaler contains an antibacterial medicine called tobramycin (an aminoglycoside).



The TOBI Podhaler is now available as an alternate delivery method to the nebulized Tobramycin.

The TOBI Podhaler is a plastic, handheld inhaler device that contains a dry powder formulation of tobramycin. The Podhaler is used to deliver 1 dose of TOBI in the morning and one dose in the evening. One dose consists of 4 capsules. Each capsule is administered separately and contains 28mg of tobramycin, for a total dose of 112 mg of per dose. The two doses (of 4 capsules each) should be inhaled as close as possible to 12 hours apart and not less than 6 hours apart. TOBI Podhaler does not need to be stored in a refrigerator and, unlike nebulized TOBI treatments, does not require a power source to operate the device.

The recommended dosage of TOBI Podhaler for both adults and pediatric patients 6 years of age and older is the inhalation of the four 28 mg TOBI Podhaler capsules twice-daily for 28 days using the Podhaler device. TOBI Podhaler is taken in alternating cycles of 28 days on treatment followed by 28 days off treatment.

For more information and demonstration video, please visit the TOBI Podhaler web site at: www.tobipodhaler.com

Research Corner

It is Children's CF Research Program's mission to improve the quality of care we provide and to improve the overall quality of life for the patients we serve. Thank you to all the CF families who have donated their time and energy participating in clinical trials. You are the key to finding a cure. Without your help, research cannot move forward. We need your continued participation to move promising therapies from the testing phase to the people who need it most.

Research Contacts

To learn more about the Cystic Fibrosis Research contact:

- Mahrya Johnson: Office 612-813-6384; Email: mahrya.johnson@childrensmn.org
- Andrea Gruber: Office 612-813-6661; Email: andrea.gruber@childrensmn.org

CF Foundation Research Updates

If you would like to learn more about the CF Foundation research activities, please visit their website at <http://www.cff.org/research/>

CF Listserv Update

Please remember to submit email address changes by completing a listserv form and handing it to your clinic nurse. These forms can be found in the lobby of CRCCS, or by asking Mary Sachs or Sandy Landvik.



Nutrition Basics



Need new snack ideas?

- Veggie Stix – a great salty snack!
- Hummus and veggies – high in protein
- Apples topped with peanut butter and chocolate chips
- String cheese wrapped in deli meat



Featured Recipe

Cheesy Bacon Bombs

- 1 can (8ct.) Pillsbury Grands Flaky Layers Biscuits
- Cubed Mozzarella Cheese (1-1" cube per Bomb)
- 2 lbs. of Bacon (1 slice per Bomb)
- Sticks – skewers or toothpicks
- Oil for frying

Directions:

- Cube up the Cheese, and cut each Biscuit into Fourths.
- Place one piece of Cheese inside a Biscuit quarter, and roll it up in there, nice and tight...
- Wrap each rolled Bomb in a slice of Bacon, and secure it with a skewer or toothpick...
- In a med/large pot, heat up approx. 2" of Oil (to 350 degrees) and fry them up in small batches. Maybe one or two at a time, the oil will expand so stay close...
- Drain them on some Paper Towel, but serve them up good and warm, so they do this...



Back to School Nutrition Basics

Just when you finally got your summer groove on, school snuck up on us! Here are some nutrition "don't forgets" when heading back to school:

- Check with your school nurse about the administration of enzymes for meals and snacks. (Make sure your child has enough time to get to the nurse to get their pills and still make it to lunch with their class.)
- Is your child not a good eater at school? No worries! They can make up those calories in their after school snack, dinner, or bedtime snack.
- Remember, skim chocolate milk is a great substitution for whole milk. It has about the same amount of calories!
- Can't make it until lunch? Pack snacks – beef jerky, crackers, granola bars, dried fruit and nuts are all good choices.
- Need to freshen up lunch brought from home? Kids love things on a stick – load up your favorite fruits and vegetables to make kabobs, and don't forget the dip! Also, try cutting sandwiches into shapes using a cookie cutter. The more interesting you make their lunch, the more apt they are to eat it and not "trade" it or throw it away!

Protein Options

Looking for more protein in your child's diet? Select sources that come from food versus protein powder. Protein powder is more appropriate for adults and excess protein can put stress on your child's kidneys. **Plus, protein from food is cheaper!** Milk, cheese, Greek yogurt, eggs, beans and nuts are all great examples of higher protein foods.



Meet the team

Megan Erickson

To better accommodate the growing nutrition needs of our patients, the CF Team has added another dietitian!

Meet Megan Erickson!



Education: Megan Erickson, RD, LD is finishing her master's degree in Nutrition at Texas Women's University. She is a college graduate of South Dakota State University and completed her dietetic internship at the Michael E. DeBakey VA Medical Center in Houston, Texas. She had the opportunity to complete a clinical rotation at Texas Children's Hospital in Houston, TX where she worked with children with cystic fibrosis.

Hobbies: Megan enjoys singing, watching movies, riding bike and spending time with her husband, friends and family in her free time. She loves to cook and try new foods and recipes. She also has a niche for decorating and DIY projects.

Where did you grow up: Megan grew up on a farm from the small town of Bristol, South Dakota. She graduated high school with a class of only 37 people!

Favorite Food: Megan has a secret love for ice cream, lasagna and chocolate.

Fun Fact: Megan and her husband are high school sweethearts and became first time homeowners this summer!

She is very excited to be a member of the CF Team and looking forward to meeting you!

Megan can be reached at 612-813-7591 or by email at Megan.Erickson@childrensmn.org.

A SNEAK PEAK

..into a new nutrition handout coming your way

Who knew biscuits were so awesome? Not only are they a "tube" food (high in calories!) but also very versatile. ***Be sure to ask for the new biscuit handout at your next clinic visit!***

Strawberry Shortcake

- Brush 8 biscuits with milk and sprinkle a heavy layer of sugar
- Bake as directed.
- Slice up strawberries and sprinkle with ½ cup sugar.
- Fill cooled biscuits with strawberries and whipped cream.
- Enjoy!

