

April 2017

The CF



Breeze

"CF wisdom & inspiration for CF families"

CF Transition Program



The CF team is committed to helping our patients and families make a smooth transition from pediatric to adult health care. Our goal is to help our patients develop the skills and knowledge they need to manage their CF care independently and confidently as they transition into adulthood.

We will begin working with your child at a young age to prepare them for the expectations in care management at each developmental stage. We also work with you to help encourage, guide, and empower your child during this process. We are here to support you!

The booklet you will receive is divided into seven stages. Each stage will provide a framework for your child to gradually become more independent and gain confidence in managing their care.

During the time of transition, we will collaborate with you and your child regarding the age for transferring to an adult provider. We will assist with this transfer process by helping to identify an adult provider, sending medical records to coordinate care, and communicating with the adult CF team about your child's specific needs.

Please contact your CF team with any questions. We are on this journey with you!

Upcoming Events

CF Parent Support Group

- Monday, May 22
- Monday, July 24

Group meets from 7 p.m. to 8:30 p.m. at Children's Minneapolis in the Children's Specialty Center, Room 506 (A call in number is also available at 612-215-9496 Password 12345.)

For CF Foundation activities, please 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.

CF Family Council Seeking New Parent Members

The CF Family Council (CFFC) at Children's Minnesota exists to foster partnerships between children with Cystic Fibrosis, their families, their care team and the CF Foundation to enhance both the patient and family experience with all facets of care, as well as, improve health outcomes of the children through empowerment, communication and education.

The team meets on the Children's Campus, in the evening, on the 1st Monday every other month. You will receive free parking, as well as receive reimbursement for your mileage to and from the meeting, and applicable child care expenses.

If interested in joining this fun and energizing team, please contact Sandy Landvik at 612-813-3304.



Bone Health and Cystic Fibrosis

Why do we care and what can we do?



When we consider health with CF we typically think about the lungs and gastrointestinal tract. One area we do not want to overlook is our bones! People with CF are at an increased risk of developing osteoporosis (brittle, fragile bones) and osteopenia (reduced bone mass) which can cause weak and brittle bones. As life expectancy for people with CF increases it becomes ever more important to think about maintaining whole body health.

Why are people with CF at increased risk?

- **Malabsorption** – Challenges with absorbing adequate nutrients can lead to a shortage of building blocks needed to build and maintain strong bones.
- **Low body weight and delayed puberty** - Increased risk of fractures can occur with low body weight. Delays in puberty related to poor nutritional status can result in less bone being made during adolescence at the time when bone development is rapid.
- **Inflammation** – Inflammation during times of illness can lead to loss of bone mass.
- **Steroid medications** – At times, using steroids during illness is very important for treating lung disease. However, long-term steroid use can contribute to weakening of bones.
- **Blood sugar control** – In the setting of CF related diabetes, keeping blood sugars under good control allows the body to effectively use the food and nutrients consumed to build and maintain strong bones.

How can we protect our bones and keep them strong?

Nutrition – Maintain a well-balanced diet and work to achieve a healthy weight for your height

- **Enzymes** – Be sure to take your enzymes and let your CF team know if you having signs of malabsorption (such as loose oily stools or stomach pains) to help decrease your risk.
- **Calcium** – One of the main building blocks of bones. Children and adolescents need the greatest amount of Calcium because they are growing rapidly and building bone strength. The best sources of calcium include dairy products, fortified juices and fortified foods such as cereal. Children greater than 9 years old need 1300 mg/day. If your child does not consume dairy products talk with the CF dietitian about how to ensure they are getting enough calcium.
- **Fat soluble vitamins (ADEK)** – Taking your CF multivitamin helps to ensure that you are getting the nutrients needed to build strong bones in a way that is more easily absorbed for people with CF. Your multivitamin also includes other nutrients such as Zinc that are helpful for building strong bones.
- **Vitamin D** – Having enough Vitamin D in the bloodstream helps with calcium absorption and utilization in the body. This is why your CF center checks Vitamin D levels at your annual lab draw. If your levels are below 30 ng/mL you will be asked to take an additional Vitamin D supplement. Make sure the supplement you buy is called Vitamin D3 (cholecalciferol). This form is more effectively used by the body. Some foods such as milk are fortified with Vitamin D, however, consuming these alone often does not effectively help us meet our daily needs and maintain normal blood levels of Vitamin D.
- **Protein** – Protein helps provide building blocks for all tissues in the body and bones are no exception. Including protein from meats, eggs, fish, dairy, nuts, beans and whole grains with each meal and snack helps to ensure we are getting enough to maintain strong bones.
- **Limit caffeine intakes** – caffeine can cause the body to waste nutrients through increased urination due to its diuretic effect.

Fitness - Staying active helps to build strong bones during childhood and adolescence and also helps to maintain bone strength as we age.

- It is recommended that all children get 60 minutes physical activity per day.
- Include a variety of activities such as walking, jogging, weight lifting, yoga, dancing, basketball, jump rope etc. to use the muscles, lungs, heart and increase bone strength.



Featured Recipes

Strong Bodies Strong Bones Breakfast Parfait

Get your morning off to a great start with this high calorie/high protein treat that features ingredients packed with calcium and protein to help maintain and build strong bones

Ingredients:

- 1 cup full fat Greek yogurt – flavor of your choice
- ½ - ¾ cup calcium fortified cereal – flavor of your choice
- ½ cup berries/fruit
- 1/3 cup chopped nuts

Directions:

In the bottom of a small bowl or cup, layer:

- 1/3 cup Greek yogurt.
- Sprinkle half of the measured cereal, fruit and nuts on top of yogurt.
- Layer another 1/3 cup of Greek yogurt.
- Sprinkle remaining cereal, fruit and nuts on top of yogurt.
- Finish with remaining yogurt and add fruit for garnish as desired.

This dish is easy to make and delicious. It provides 17-19 grams of protein and approximately 40% of your daily calcium needs.



Try Using Homemade Granola

Easy Healthy Homemade Granola Recipe

Use raw, organic ingredients whenever possible. These measurements are flexible; don't worry too much about being exact.

Ingredients:

- 2 cups raw, whole rolled oats (aka old fashioned oats), preferably organic
- ½ cup raw nuts, chopped
- ¼ cup raw seeds (sunflower or pumpkin seeds are great)
- ½ cup unsweetened dried fruit, chopped (optional)
- 2-3 tablespoons grade-b maple syrup or raw honey (or a combo of both)
- 2 tbsp virgin coconut oil or other healthy cooking oil
- ½ tsp vanilla extract or almond extract
- 1 large pinch fine sea salt

Directions: Preheat the oven to 300° F. Combine all ingredients in a mixing bowl and use your clean hands to mix well and toss to coat; it will be sticky and messy but that's the fun part. The coconut oil might be liquid or solid depending on the temperature of the room you are in (it has a melting point of about 75°F.) Your hands will warm it up and melt it into the mixture if it's solid, just be sure to mix it all through the other ingredients so there aren't any chunks of oil left. Spread the mixture in a thin layer on a baking sheet and bake for 10 minutes, until very lightly toasted. Cool before serving or storing. This granola can be kept in an airtight container in a cool, dry place for up to 2 weeks.

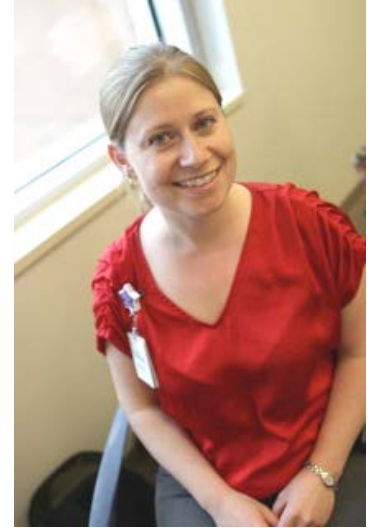
Taken from: <http://www.elizabethrider.com/easy-healthy-homemade-granola-recipe/>



A Fond Farewell From Mahrya Johnson

It is with a heavy heart that I am writing to let you know that I have left Children's in pursuit of new opportunities in the field of research management and administration. I have had twelve of the most wonderful years at Children's, more than I can express in words. It has been an incredible experience working with your amazing children and watching them grow. You all are truly the key to finding a cure for cystic fibrosis, and I am so happy to say that I was a part of that mission. I leave knowing that you will all be very well supported in future research opportunities by the wonderful, caring and compassionate CF clinical and research teams.

Sincerely,
Mahrya Johnson



Medical Research Updates

Studies Open for Enrollment:

1. Saline Hypertonic In Preschoolers (SHIP-001): Patients with CF ages 36-72 months may be eligible. **Open for enrollment and we are looking for 1-2 more families! If your child currently uses 3% or 7% Hypertonic Saline, they may still be eligible for the study.**
2. The Impact of Insulin Therapy on Protein Turnover in Pre-Diabetic Cystic Fibrosis Patients. We are working on this 8-week study in collaboration with the University of Minnesota. Seeking 10-25 year olds with abnormal glucose tolerance test results who have not been diagnosed with CFRD. **Open for enrollment!**



To learn more about the Cystic Fibrosis Research Program contact:

Christine Benoit at 651-220-6254 or via email at Christine.benoit@childrensmn.org

Anne Mills at 612-813-7756 or via email at anne.mills@childrensmn.org

Elizabeth Franck Thompson at 612-813-6347 or via email at elizabeth.franckthompson@childrensmn.org



Physical Therapy Grant

PT services now available at no cost

The Children's Minnesota CF center was chosen to be 1 of only 31 centers in the US to receive a grant to fully fund a physical therapist (PT) for our outpatient CF clinic to see kids 1 year and older.

Physical therapy has been shown to provide many benefits for CF patients.

PT's will help work on the "over use" of breathing muscles which leads to muscle weakness of the core muscles and poor posture.

The physical therapist will also educate families on ways to help the breathing muscles work more efficiently and will work with you and your child to improve their flexibility, strength and activity tolerance for an overall better quality of life.

They will also address pain and assess whether stress urinary incontinence (SUI) is an issue that is occurring. SUI is a problem of leaking of urine which can occur in some female teens.

Exercise is about wellness! Try using PT services during your next appointment. The PT office is located in the Children's Specialty Center on the second floor, Suite #267.

For questions, please contact **Julie Christiansen 612-813-6376**.



To schedule an appointment with our Physical Therapy, call **612-813-6709**.

Note: Consider scheduling an appointment one hour before or after any CF clinic visit to save on travel.

Calling all Cooks!

We still need your help! We are hoping to create a CF cookbook full of high calorie/high protein recipes that our families at Children's have found to be winners in their own homes. This is an opportunity to share your tips and tricks and help provide some fresh ideas for our families. Whether it's breakfast ideas, snacks, lunches on the go, favorite family dinners, dessert or helpful hints, we want to hear what you have to say! The sky is the limit!



Email recipes/ideas to the CF dietitian, Kate Henschel, at kate.henschel@childrensmn.org.

Recipes will be collected throughout 2017.