April 2015

The CF Breeze

"CF wisdom & inspiration for CF families"

# Annual Screening for Anxiety and Depression

The Cystic Fibrosis Foundation completed a major research study in collaboration with the European Cystic Fibrosis Society, which evaluated symptoms of anxiety and depression in children, adolescents, and their parent caregivers.

The findings showed that rates of anxiety and depression were 2-3 times higher than the rates reported in community samples. As a result, the CF Foundation developed clinical care recommendations for anxiety and depression for individuals with cystic fibrosis and their parent caregivers. The guidelines are still in draft form but are expected to be finalized and published at some point in the next six months. Here's some of the changes you can expect to see in the next six months as a result of these new guidelines:

- Children 12 years of age or older, will be asked to complete the following screening tools: Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder Questionnaire (GAD-7), and the CRAFFT screening tool which helps identify teens who are at-risk of substance abuse.
- Research has shown that there is a significant link between parental anxiety and depression, and their children's mental health. As a result, parents who have a child with CF between the ages of 7-11 will be offered the screening tools.
- Depending on the score, people will either: complete the assessment at their next annual visit, be provided with educational materials about depression/anxiety, or meet with the Social Worker to explore what factors are contributing to the score, and/or offer a range of support services to improve the depressive or anxious symptoms.

As always, if you or a loved one is experiencing a mental health crisis, please call 911 or go to the closest emergency room.

If you have any questions about this new process, please contact Lacie Johnson at 612-813-6839 or by email at: lacie.johnson@childrensmm.org.

## Upcoming Events

**CF Community Parent Support Group meets the fourth Monday of each month from 7 p.m. to 9 p.m. at Children's Minneapolis.**

- Monday, April 27
- Monday, June 22
- Monday, July 27

*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.***

# Ronald McDonald House

*Children's Hospital and Clinics of MN – Minneapolis Location*

Four years ago, Children's Hospital and Clinics-Minneapolis became the 5th hospital in the world to open a Ronald McDonald House (RMH) in a hospital! Since that time, the House inside the Hospital has served more than 5600 families. Families have really liked this onsite amenity. Here's what you should know about RMH if your child becomes hospitalized:

| Question | Answer |
|---|---|
| What is Ronald McDonald House? | Ronald McDonald House (RMH) is a resource available to the family members of a child who is hospitalized. The RMH is designed to feel like a home away from home. At RMH, families can relax in front of the fireplace, prepare a meal in the kitchen, have a cup of coffee, access the food pantry, watch TV, play video games, relax on the patio, use the exercise equipment or check email. |
| Can families with a child with CF in the hospital have access to RMH? | YES! On the 10th day of your child's hospitalization you can be referred to use RMH. If your child is admitted to the intensive care unit, you would have immediate access. |
| Does RMH provide meals? | YES! Volunteers prepare and serve meals throughout the week for registered families from 11:30am-1pm and 5:30-7pm. Meals are provided on a first-come first-served basis. Meal schedules and menus are available within RMH and on the units. There is also a fully stocked food pantry available for families to use. |
| Who Can I Contact About Using RMH? | Please talk to a nurse, social worker, stop by the RMH front desk, call the Ronald McDonald House at 612-874-4800, or email: mikeo@rmhtwincities.org. |

Ronald McDonald House Charities

# Vest Treatments

## *High Frequency Chest Wall Oscillation*

High Frequency Chest Wall Oscillation (HFCWO) is a device (vest) that has been used as a method of airway clearance for individuals with cystic fibrosis (CF) for many years, and has been shown repeatedly to be very effective at airway clearance and improving pulmonary function.

There are three well-known manufacturers of 'vest' devices, and interestingly enough, all three are located in the Twin Cities area:

- Hill-Rom - The Vest® Airway Clearance System (Arden Hills)
- Respirtech - inCourage® System (St. Paul)
- ElectroMed - SmartVest® Airway Clearance System (New Prague)

The effectiveness of HFCWO is directly related to the change in airflow created by the device being used. HFCWO works by increasing airflow velocity in the lungs to create cough-like shear forces that decreases the thickness of mucus/secretions in the lungs, making them more mobile. Researchers have described the beneficial effects of oscillating airflow in mobilizing pulmonary secretions and have also observed that during HFCWO therapy, airflow that is pushed out of the lungs is faster than airflow coming back in. The increased airflow helps to push mucus toward the larger airways where it is more easily cleared by cough. This supports why it is important to do periodic coughs or huff/coughs during vest therapy.

The HFCWO device must be able to generate oscillations vigorous enough to increase flow rate in the airways to loosen and mobilize secretions. One way to tell if the airflow is vigorous enough is to listen to the sound of the person's voice when speaking while using the vest; their voice should change. If the patient's voice doesn't change or changes minimally, the flow rate is probably not increased enough to move and thin their mucus. If you notice that your child's voice does not change while using the vest, please contact John Plante or the Children's Respiratory Therapy department.

**What about the new battery-powered and portable Afflovest?**

The Afflovest is a new HFCWO device manufactured in Texas that is battery-powered and portable. The Afflovest was demonstrated for CF Respiratory Therapists at the National CF conference in October 2014. The therapists agreed that the oscillations generated by the Afflovest were not vigorous enough to increase flow rate to be able to thin and mobilize secretions. Additionally, this portable vest has not been tested on patients with CF. This is an important distinction between Afflovest and the other three currently on the market, as research has demonstrated that The Vest®, inCourage®, SmartVest® are all effective in treating patients with CF. Therefore, more research is needed on the Afflovest before it will be recommended for our patients.

Remember to register for your Great Strides Walk
www.cff.org/greatstrides

## *Featured Recipes*

## Crock Pot Mac & Cheese

Ingredients
4.5 cups elbow macaroni, uncooked
2 cups cheddar cheese, shredded
1 – 8 oz pkg cream cheese, cut into cubes
4 cups whole milk
Salt and pepper to taste

Instructions:
Combine all the ingredients in the bowl of a slow cooker; cover and cook on low for 3-4 hours
Stir throughout cooking time to combine ingredients

Tip-- Can add more cheese for a cheesier version or top with bread crumbs for a crunchy finish!

Nutrition – per serving (makes 8 servings)
508 calories
20 grams protein
24 grams fat
56 grams carbohydrate

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## Peanut Butter Balls

Ingredients
1 cup butter
2 cups peanut butter
1 pound powdered sugar

Instructions:
Mix peanut butter and butter.
Add powdered sugar.
Roll into balls (makes approx. 40 1 inch balls)
Refrigerate until ready to eat.

Tip-- Quick and easy and perfect for on the go! Top with sprinkles, M&M's, chocolate chips, coconut or chopped peanuts!

Nutrition – 2 per serving
150 calories
3 grams protein
10 grams fat
14 grams carbohydrate

## Medication 101

### *Antioxidant Therapies for CF*

You hear a lot about antioxidants and how they can prevent disease. In recent years, the Cystic Fibrosis Foundation has funded both laboratory and pre-clinical research studies on antioxidant therapies for cystic fibrosis (CF).

Antioxidants may have a role in the slowing or prevention of CF lung disease. A healthy diet, including fruit and vegetables supplemented by fat-soluble vitamins, can boost the CF patient's antioxidant protection.

In people with CF, however, the digestion does not always guarantee proper nourishment since mucus tends to clog the pancreas. Therefore, researchers are looking for alternative ways to deliver antioxidants to CF patients. One compelling strategy is to supplement the fat-soluble vitamins A, D, E and K. Another strategy is to administer oral N-acetylcysteine, or NAC, which is a building block for the antioxidant glutathione.

The CF Foundation is committed to moving new effective antioxidant therapies forward as quickly as possible. The CF Foundation continues to work with physicians and scientists to design and start a double-blind, placebo-controlled clinical trials.

*Abridge version from www.cff.org*

We are pleased to announce

## Dr. Anne Griffiths

has joined Children's Hospital and CRCCS as a Pediatric Pulmonologist beginning October 27th, 2014.

Dr. Griffiths attended medical school at the University of Minnesota and recently completed her Pediatric Pulmonology fellowship at Anne & Robert H. Lurie Children's Hospital in Chicago, Illinois, where she also completed her pediatric residency. As a former physician liaison to child life specialists, she has an appreciation for the child's unique experience of receiving medical care. Dr. Griffiths returns to Minnesota with her husband and two children.

## 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 in April 2015.**

2. A Long-Term Prospective Observational Safety Study of the Incidence of and Risk Factors for Fibrosing Colonopathy in US Patients with Cystic Fibrosis Treated with Pancreatic Enzyme Replacement Therapy: A Harmonized Protocol Across Sponsors

3. Clinical Outcomes in Pediatric Patients with CFTR-Related Metabolic Syndrome (CRMS) for patients with CF or CRMS and were diagnosed by newborn screening between 2006-2015. The Cystic Fibrosis Foundation has developed Practice Guidelines for managing patients with CRMS, but we would like to improve our understanding of CRMS. Long-term data on outcomes for patients with CRMS is needed to help patients and their families understand what to expect and for appropriate medical management.

**More New Studies Coming in 2015**

**To learn more about the Cystic Fibrosis Research Program contact:**
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