November 2012

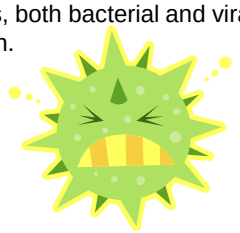
The CF Breeze

"Wisdom & inspiration for CF families"

Germ Management

I like you, but not your germs….

If you are living with cystic fibrosis (CF) or are raising a child with it, you know how challenging managing the disease can be. The routine on a healthy day has many demands. When battling illness, the demands become even greater due to increased treatments, additional medications and more sleepless nights. There are some simple tasks that people with CF can perform to decrease their risk of catching germs, both bacterial and viral, that can lead to infection.



** adapted from the Cystic Fibrosis Foundation Education Committee. Respiratory: Stopping the Spread of Germs*

Scrub-a-dub-dub! Hand hygiene is vitally important to stop the spread of germs. Hands should be cleaned with antibacterial soap and water after touching anything that has come into contact with mucous, sputum, phlegm or any other body fluids. Another method for hand hygiene is alcohol-based hand sanitizer. Often times, this method is quicker, more easily accessible and has the potential to kill more germs. A good rule of thumb to follow is: if you see dirt on your hands, use soap and water; if you do not see dirt, use hand sanitizer.

Keep your equipment clean! Clean and disinfect all equipment that is used for inhaled medicines on a daily basis. It is vital to have an established routine for disinfecting equipment after use. Refer to the equipment owner's manual for exact direction, but know that equipment is not considered disinfected unless these steps have occurred:

- Hands have been cleaned
- Nebulizer parts have been cleaned (wash the parts with hot, soapy water before disinfecting)
- Nebulizer parts have been disinfected (boiling, microwaving, and sanitizing rinse through the dishwasher are the most common methods)
- Nebulizer parts are air-dried.

Raise an arm and get vaccinated! Everyone should get the Centers for Disease Control and Prevention (CDC) recommended vaccinations, including an annual flu shot. Vaccinations are especially important for people with CF. Although people with CF are not more susceptible to viral infection, once infected they are more likely to get much sicker and will have to fight longer and harder to get rid of the viruses. Likewise, caregivers of individuals with CF need to also focus on their own infection protection, so as to not expose unwanted germs to the individual with CF.

Set good boundaries! Stay clear of others that are sick. Keep children with CF home if others in their classroom are ill. The same rule applies for family gatherings. In the event that other family members are ill during the holiday season, be prepared with alternative plans. An at-home healthier holiday celebration with your immediate family may be the best alternative.

Your CF care team is a great resource to help with infection control. Not only do they have ideas for preventing the spread of germs, they also will provide support in all aspects of CF. Just as managing the demands of CF can be overwhelming, so to can be understanding and implementing the guidelines for infection control. Make sure to become educated about the necessary actions to prevent infection, and seek support from your CF team as needed.

Upcoming Events

November 26 - CF Parent Support Meeting
Children's Minneapolis

January 28 - CF Parent Support Meeting
Children's Minneapolis

February 2 – Climb for a Cure
IDS 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. Please contact Mahrya Johnson at Mahrya.Johnson@childrensmn.org to be added to the distribution list.

Immunizations

Protecting your family from infections circulating in Minnesota….

Children (and adults) receive many immunizations in their lifetime. With frequent well child exams at your pediatric clinic, you can keep up with the recommended vaccines and vaccine schedules. All children should receive standard immunizations at well-child exams through their infancy and toddler years along with further "booster shots" with their well-child exams between 4-6 and 12 years. Middle and high school children are also offered optional vaccines to protect against potential future illnesses they may be exposed to over their lifetime.

This article will focus on two current vaccine preventable infections circulating currently in Minnesota (Pertussis and Influenza) and what you can do to protect your child with cystic fibrosis.

Pertussis

Pertussis, which is more commonly known as whooping cough, is an infectious disease that has been on the rise in Minnesota this year. It is caused by a bacterium called *Bordatella pertussis* and is spread through the air by infectious droplets. The early stage of infection has symptoms which are similar to the common cold: runny nose, low-grade fever, and a mild cough. After 1-2 weeks the symptoms can worsen to include bursts or a "paroxysm" of numerous, rapid coughs. At the end of the cough, there can be a long inhaling effort that is characterized by a high-pitched "whoop". Infants and children can often appear ill and distressed and may vomit with the cough. However, not all children with pertussis have the classic "whoop" accompanying the cough.

The illness usually persists 2-6 weeks but may last months with paroxysms of cough that may recur with other respiratory infections. The disease is typically milder in adolescents and adults but they are still able to transmit the infection to others, including infants who are not completely immunized.

Keeping up to date on recommended vaccines, using good hand washing and avoiding people with cough are ways to prevent this illness. Infants and children typically receive pertussis vaccine at 2, 4, and 6 and between 15- 18 months with a booster dose at 4-6 years and 12 years. All adults, especially parents of children with a chronic illness like CF, should receive a one time dose of Tdap (Tetanus and diphtheria toxoids with pertussis) as soon as it is feasible.

Influenza

Influenza, unlike pertussis is a viral illness that circulates yearly, usually from October to May with peaks in the months of January and February. There are 2 main types of influenza (flu) virus that routinely spread through people, A and B. The flu is spread through droplets when people cough, sneeze or even talk. Less often, individuals can also catch the flu by touching an object with flu virus on it and then touching your nose or mouth. Symptoms may include: fever, cough, chills, body ache, fatigue and vomiting (which is seen more commonly in young children).

Children with CF who are 6 months or older should receive 2 doses of the flu vaccine, 1 month apart, the first year they are immunized and yearly thereafter. It usually takes about 2 weeks after receiving the vaccine to develop antibodies which provide protection. All adults (parents, caretakers, grandparents, etc.) who have close contact to infants or children with CF should receive flu vaccine. This process of vaccinating close contacts is called "cocooning" and is a way to protect especially young children who are too young to be immunized. Children with CF should receive the influenza shot (not nasal spray) as soon as it is available which will provide protection through the viral season against the influenza strains that are a part of the vaccine. These strains may vary from year to year.

Information from the Immunization Action Coalition www.vaccineinformation.org, and Centers for Disease Control and Prevention http://www.cdc.gov

Research Corner

Each year our center receives a report from the CF Foundation Registry. This is a result of you / your child voluntarily participating in the data entry.

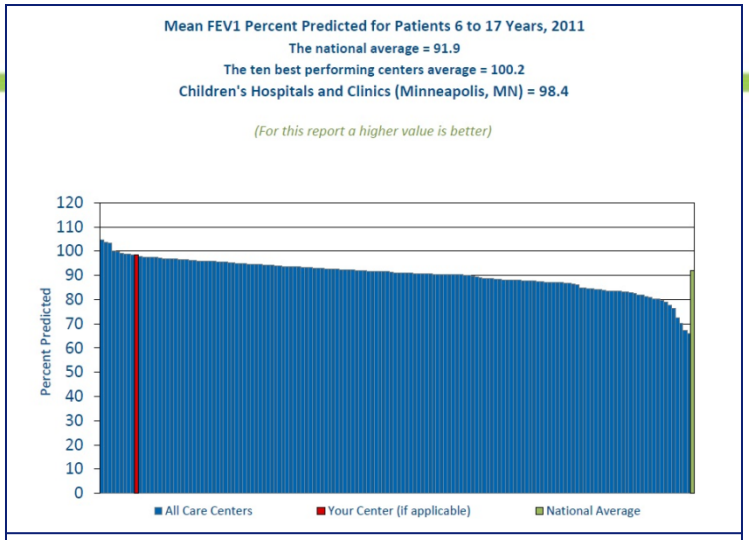
These slides represent the pulmonary and nutrition outcomes for our Center for the 2011 year. Research has shown a direct correlation between BMI (body mass index) and lung function. "The better the BMI the better the lung function."

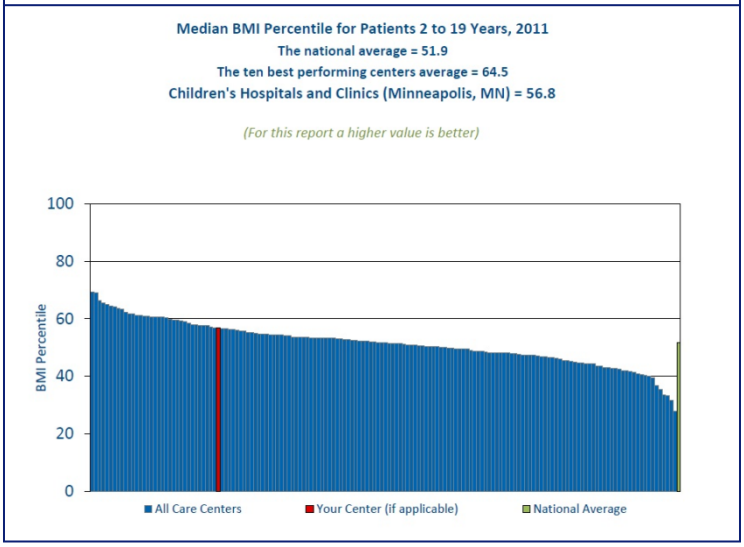
The FEVI slide shows the lung function in our center for the ages of 6-17 to be in the top ten compared to all the centers in the USA. Normal lung function in the general population is 80-120%. Children's is at 98% for our patients with cystic fibrosis!

The BMI slide shows Children's data at about the 57%. The goal we are aiming for is the 50 %.

These two slides show how well our center performs compared to the rest of the country. It is a tribute to the hard work you do to improve the outcomes of this disease.

More information on Children's Center data is located on the CFF web site at www.cff.org.





It is Children's CF Research Program's mission to not only improve the quality of care we provide, but to improve the overall quality of life for the patients we serve. Thank you to all the families of CF patients 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 them most.

Studies open for Enrollment

- Evaluation of Sleep in Children and Adolescents with Cystic Fibrosis
- Baby Observational and Nutritional Study (BONUS-IP-11)
- (Twin/Sibling) Genetic modifiers system of cystic fibrosis study
- 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
- Early MRSA therapy in CF – culture based vs. observant therapy (treat or observe) (STAR-too – STaph Aureus Resistance – treat or observe)

Staffing Updates

Please join us in welcoming Ashley Young to our research team! She will be helping our research team in many capacities.

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

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

Nutrition Basics

Featured Recipe

As adapted from the CF Family Advisory Council of Altanta, GA "This Eating Stuff is Hard Work" A Cystic Fibrosis Recipe Book

Paula Dean's Creamy Macaroni and Cheese

4 cups cooked elbow macaroni, drained (approx 2 cups uncooked)
2 cups grated cheddar cheese
3 eggs, beaten
½ cup sour cream
4 Tbs. butter, cut into pieces
½ tsp. salt
1 cup milk
1/3 cup bacon bits

Preheat oven to 350 degrees. After macaroni has been boiled and drained, add cheddar cheese while macaroni is still hot. Combine remaining ingredients and add to macaroni mixture. Pour into casserole dish and bake for 30 to 45 minutes. Top with additional cheese and bacon bits if desired.

Crock Pot Version

Ingredients listed above plus
½ cup grated cheddar cheese
1 can condensed Cheddar cheese soup
½ tsp. dry mustard
1/3 tsp. black pepper

Cook the macaroni until tender and drain. In a medium saucepan, mix butter and cheese. Stir until the cheese melts. In a slow cooker, combine cheese/butter mixture and add the eggs, sour cream, soup, salt, milk, mustard and pepper and stir well. Then add drained macaroni and stir again. Set the slow cooker on low setting and cook for 3 hours, stirring occasionally.

Nutritional Information (per serving, divided into 12 servings)
Calories 270
Fat 16g
Carbohydrates 18g
Protein 10g
Sodium 435mg

12 Tips to Prevent Weight Loss During the Holidays

The holidays are a great time of year to either gain weight or keep from losing weight. Please use the list below to help you keep the weight up during the holidays.

1. Keep your enzymes handy! If you are grazing (or eating throughout the day), or eating an extremely large meal remember additional enzymes may be needed. Remember to take extra enzymes every 45-60 minutes.
2. When shopping at the grocery store enjoy all of the yummy samples . (Remember to take your enzymes though!)
3. Eat warm cookies straight from the oven!
4. Avoid missing meals and snacks if you're out shopping all day. Pack snacks like trail mix, granola bars, energy bars, nuts, dried fruit, cheese and cracker packs, muffins, or pudding snacks to help tide you over.
5. Add ice cream or whipped cream to pies and hot chocolate. Make your own whipped cream by whipping 1 cup of whipping cream until stiff peaks form, add ¼ to ½ cup of sugar and mix well. (Store in refrigerator for up to 4 days.)
6. Put extra butter on potatoes, bread, veggies and stuffing.
7. Have your child/teen help plan the holiday menu. Intake improves if they get to pick their favorites!
8. Add chocolate chips, nuts, coconut, dried milk powder, and/or dried fruit to baked goods.
9. Serve pretzels, chips, veggies and fruit with dips instead of eating them plain.
10. Freeze your favorite holiday treats to enjoy for months to come.
11. Enjoy high-calorie drinks during the holidays such as hot chocolate or Chai Tea made with whole milk and topped with whipping cream, eggnog, warm vanilla milk, or hot apple cider drizzled with caramel topping.
12. Don't skip the meat and cheese trays, they are a good source of calories and protein.

A great new CF Recipe Book with several tips and ideas is available at:
http://www.cff.org/LivingWithCF/StayingHealthy/Diet/FoodIdeasRecipes/