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University of Wisconsin
Clinical Sciences Center

Center Focus

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Newsletter of the
Cystic Fibrosis Center

New Infection Control Guidelines Coming in 2014

The Cystic Fibrosis Foundation produced Infection Control guidelines in 2003. Those guidelines utilized available data at that time and there was anticipation that the guidelines would need to be updated. Over the past 12-18 months, infection control experts have met and new infection control guidelines have been produced. These guidelines are not yet finalized, but should be final soon.

One of the new scientific discoveries in the past decade is that infectious particles can travel for up to 6 feet or more. This has major implications for persons with CF. The overarching goal of the new guidelines is to keep all patients safe. Thus, in 2014, we will be implementing the new guidelines in our clinic and for patients that are hospitalized.

Some of the highlights of the guidelines are:

- Persons with CF should perform hand hygiene (meaning, using Purel or hand-washing with soap and water) upon arrival in clinic, when leaving clinic and after hands become contaminated with respiratory secretions
- All care providers in clinic will wear a disposable gown and gloves for every patient, regardless of the results of the culture.
- Similarly, for the duration of inpatient hospitalizations, all care providers will wear gowns and gloves when going into a patient room.
- Patients coming to clinic should wear a face mask on arrival to the front door of the building and keep the mask on until they are in their exam room. The mask should be worn again upon departing clinic.
- For patients who are hospitalized, they should wear a face mask whenever they leave their inpatient room.
- Unrelated patients with CF should not be in a common area such as a classroom or attend social or fund-raising events.

Although these guidelines may sound harsh, the goal is to keep all patients safe

Cystic Fibrosis Lifestyle Foundation (CFLF) Recreation Grants

Here at the CF Center, we can prescribe medications and make recommendations for healthy eating and a healthy lifestyle (such as an adequate amount of sleep and no exposure to cigarette smoke). However, one of the other aspects of a healthy lifestyle are physical activities. One can do many activities on your own at no cost, however other activities such as joining a gym or fitness classes have a price tag associated with them.

What if you cannot afford to join or gym or other activities? Here is a nifty way for these activities to be paid for. You can apply to the Cystic Fibrosis Lifestyle Foundation (www.CFLF.org) for a grant of up to $500 per year. If your grant is accepted, then the CFLF will directly pay for activities such as:

- Swimming lessons
- Rock climbing lessons
- Martial arts classes
- Water aerobics classes
- Gym membership
- Ski/snowboard pass
- Triathlon training camp
- Sports team/league fees
- Horseback riding lessons/leasing
- Surfing lessons
- Yoga classes
- Fitness classes
- Dance classes
- Summer camp
- Sports camp
- Marathon fees
- Golf fees

Go to the above website and complete the basic information, essay questions and contract. You will also need to provide a photo of yourself in which you are doing a favorite activity. Your care provider at the CF Center will need to complete a section of the application. If your grant is approved, then payment will be sent directly to the activity provider (i.e. gym facility, camp, dance studio, etc.)

Wisconsin Chapter Cystic Fibrosis Foundation News

Hello Madison!

I am Tim Schmitt, the new Development Director for the Foundation in the Madison area. I am very much looking forward to getting to know everyone in the area and plan some great events. Please reach out to me with any ideas for sponsorship, fundraising, entertainment, volunteering or if you just want to meet for coffee and say hello. I am always up for an interesting afternoon to get to know all of the CF Families: ***tschmitt@cff.org*** or 800-472-7720. Keep our two major events, Great Strides on May 18th and Cycle for Life on June 1st, on your radar.

Timothy Schmitt

Development Director

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2013 CF Family Education Day

The 2013 CF Family Education Day occurred on November 2 with an excellent line-up of local and national speakers. Our national speakers were:

- Jerry Cahill, CF Ambassador for the Boomer Esiason Foundation and author of "You Cannot Fail" presented the topic "Living. Breathing. Succeeding with CF, A Life Discipline Philosophy".
- Dr. David Geller gave an excellent presentation on various inhalation medication devices, "Inhaled Therapies in CF: How to Git'r Done".
- Dr. Alexandra Quittner presented "Interventions to Improve Adherence in CF: Initial Results of the iCARE study"

The videos from these presentations should be posted to our CF Center website (http://www.uwcfcenter.org, then click on link for Family Education) in the near future.

We will be planning our 2014 CF Family Education Day. If you have any suggestions, please contact

Save The Date - November 1, 2014

The 2014 CF Family Education Day will be November 1, 2014 at the Health Sciences Learning Center (750 Highland Avenue; adjacent to the University of Wisconsin Hospital in Madison). Please make every effort to attend. We will have another exciting, informative program.

Cystic Fibrosis Center Specific Outcomes

Here is our center specific data for the calendar year 2012. There is publicly available data on all Cystic Fibrosis Centers available at the Cystic Fibrosis Foundation website (www.cff.org). Data on that website is adjusted for attained age of patients, gender, pancreatic sufficiency, race/ethnicity, socio-economic status, and age of diagnosis. As of the writing of this newsletter, the CFF website has not yet been updated to include the 2012 data. We expect that data to be publicly available in the near future. In the meantime, we now have our UW CF Center data for last year, and what follows in this article is the raw data reported to us for the calendar year 2012.

Pediatric Center

A very useful measure of lung function is the FEV1 percent predicted. For patients 6-12 years of age, the University of Wisconsin CF Center median FEV1 percent predicted is 99.7%, which is 1.8% above the national average of 97.9%. For patients 13-17 years of age, the median FEV1 percent predicted is 93.1% at UW compared to a national median of 90.8%. For patients 6-17 years of age, the UW median FEV1 percent predicted is 98.6% compared to a national median of 95.0%.

Our nutritional outcomes are expressed in terms of BMI (Body Mass Index) percentile. For pediatric patients 2-19 years of age, we strive for a BMI percentile of at least the 50th percentile. The median BMI percentile for CF patients 2-19 years of age at UW was 59.3 compared to a national average of 52.8.

Adult Center

For patients 18-29 years of age, the median FEV1 percent predicted at UW is 74.8% compared to a national average of 71.9%. For CF patients > 30 years of age, the median FEV1 percent predicted at UW is 47.4% compared to a national average of 57.9%.

In adults over 20 years of age, one no longer uses BMI expressed as a percentile. In adult patients, BMI is expressed as the actual value with the units of kilograms per meter squared. The Cystic Fibrosis Foundation goal is that males should have a BMI of greater than or equal to 23 kilograms per meter squared and females should have a goal BMI greater than or equal to 22 kilograms per meter squared. In the UW Center, the percentage of adult patients who met those goals was 44.7% compared to the national average of 45.7%

Changes to CF Vitamins

By Erin Seffrood, MS, RD, CSP, CD

The world of CF vitamins is changing rapidly. You may have noticed that you are no longer able to get the Source CF ABDEK vitamins. They came in a liquid, chewable (bubble gum flavored), and soft gel. While these vitamins were taken off the market, 3 more were added. These brands include:

- MVW Complete Formulation (orange flavored drops and chewables and a softgel)
- the dose for infants is smaller (0.5 mL until age 12 months; 1 mL until age 3 years)
- contains more vitamin K, D, and E to improve bone health and reduce inflammation
- contains more zinc to promote growth
- ChoiceFul (bubble gum flavored chewable and a softgel)
- contains more vitamin D and E
- Libertas ABDEK (drops and chewables and a softgel)

If you get your vitamins from your CF Center, you will be given the MVW Complete Formulation. If you have any questions, concerns, or comments please let us know.

Vitamins can also be obtained free of charge from the Abvie Care Forward Program if you use Creon enzymes and the Aptalis Live to Thrive Program if you use Zenpep enzymes. Ask your dietitian for more information.

Aquadeks drops, chewables, and softgels as well as the Vitamax drops and chewables are still available. Aquadek is also coming out with a TASTELESS, ODORLESS, STAINLESS powder that can be dissolved in foods or beverages. It should be on the market by June 2014. Stay Tuned!

Changes for Patients Who Are Hospitalized

For the small percentage of patients who are hospitalized, here are several changes that have occurred:

1) At home, many patients receive inhaled hypertonic saline (7% solution) twice a day. The theory behind hypertonic saline is that the extra salty inhaled solution helps to draw water into the airways. This hydrates the secretions and those secretions can then be more easily cleared. The original studies of this therapy utilized twice per day dosing, thus, that is our standard for patients at home. However, we learned at the last North American Cystic Fibrosis Conference that many centers were increasing the hypertonic saline to four times per day for patients who are hospitalized. This makes sense, as we want to maximally hydrate the secretions in the airways to aid in clearance of those secretions. Thus, we have adopted this stratagy here of adminisitering hypertonic saline four times a day for hospitalized patients.

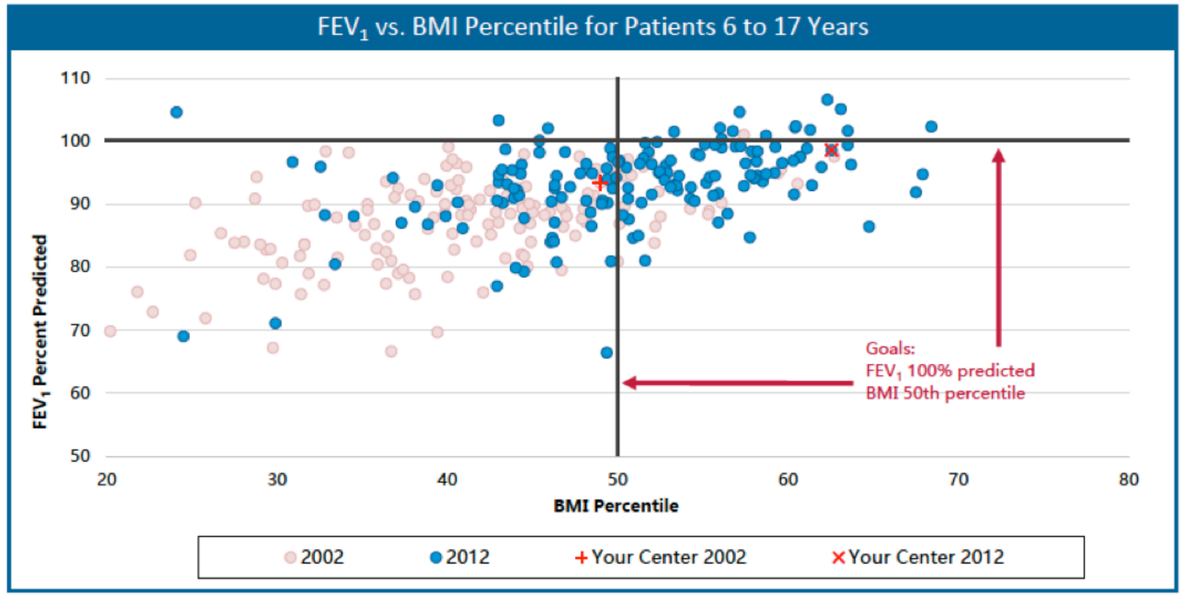
2) A focus throughout our entire hospital is to decrease the occurrence of hospital-acquired infections. In order to address this important issue, a new bathing policy became effective on December 1, 2013. This policy applies to any patient in the hospital who is over 2 months of age. In other words, this is not a CF-specific policy: this applies to ALL hospitalized patients. The new policy is a daily bath using chlorhexidine gluconate soap (Hibiclens®). Two washcloths are used for each body part. One washcloth is used for the soap, and the second washcloth is to rinse off each body part. An arm or a leg is considered a body part. So, there are two washcloths for each arm and leg, and two wash cloths for other body parts such as the chest, back and abdomen. (Hibiclens® is not used on the face or genitals). Again, the goal is to keep everyone as safe and healthy as possible.

Trends over the last four years

The following table shows data for the past four years. The UW CF Center specific data is shown first, followed by the national average in parenthesis. This allows you to see trends that are occurring both on a local and a national level.

	2012 UW (national average)	2011 UW (national average)	2010 UW (national average)	2009 UW (national average)
Median FEV_1 % predicted 6-12 years	99.7 (97.9)	98.7 (97.3)	102.3 (97.0)	100.9 (96.7)
Median FEV_1 % predicted 13-17 years	93.1 (90.8)	92.9 (90.3)	90.8 (90.0)	92.0 (89.2)
Median FEV_1 % predicted 6-17 years	98.6 (95)	96.3 (94.5)	96.0 (94.0)	97.8 (93.7)
Median FEV_1 % predicted 18-29 years	74.8 (71.9)	76.4 (71.5)	66.3 (70.0)	60.4 (70.0)
Median FEV_1 % predicted >30 years	47.4 (57.9)	51.5 (57.5)	56.3 (56.0)	50.7 (55.8)
Median BMI percentile 2-19 years	59.3 (52.8)	56.8 (51.4)	56.0 (49.4)	54.8 (48.9)
Adults over 20 years of age: % males with BMI >23 and females BMI >22	44.7 (45.7)	46.2 (44.9)	43.9 (43.3)	45.1 (42.9)

For 2012 data, the CF Foundation provided a new graph to the care centers: FEV1 % predicted plotted against BMI. Here is this graph:



Each pink circle is center data for 2002 and each blue circle is data from 2012. The UW CF Center data from 2002 is indicated by the plus sign, and the UW CF center data from 2012 is indicated by the 'x'. The vertical line is the CF Foundation goal of a BMI of the 50th percentile and the horizontal line is the CF Foundation goal of an FEV1 of 100% predicted. There are 4 blue dots that are above and to the right of the UW CF Center data in 2012. Therefore, the UW CF Center has the 5th best outcomes in the country in 2012 when combining FEV1 % predicted and BMI.

We are very pleased with these outcomes in the 6-17 year age range. We would like to be the best center in the country. It makes a difference for patients to take their enzymes, inhale DNase or hypertonic saline, perform airway clearance, etc. We want everyone to be as healthy as possible.

Meet the Staff

Sima Ramratnam, M.D., M.P.H.

Dr. Sima Ramratnam is board certified in pediatrics and board eligible in pediatric pulmonology and is an Assistant Professor at the University of Wisconsin-Madison School of Medicine and Public Health. She joined the Cystic Fibrosis Center in September, 2013. She completed her pediatrics residency and pediatric pulmonary fellowship at the Children's Hospital of Pittsburgh. She also received a Masters of Public Health at the University of Pittsburgh School Of Public Health in epidemiology during her clinical training. Her primary research interest is asthma epidemiology. Her clinical interests include childhood wheezing, asthma, cystic fibrosis, and flexible bronchoscopy.

Cynthia Wallace, L.C.S.W.

Cindy Wallace is a Licensed Clinical Social Worker with the University of Wisconsin Cystic Fibrosis, Pulmonary and Infectious Disease Adult Clinics. Before joining the CF team in October 2013, she worked at UW as a social worker with the liver transplant team. After growing up in Madison, she headed to the East Coast to complete her undergraduate and MSW degrees. After a 15-year hiatus, she moved back to Madison to take full advantage of the Midwestern quality of life. In her free time, you will find her taking hot yoga classes, testing out Paleo-friendly recipes and spending time with her family and dog.

Adding Calories without Supplements

By Andrea Magee, RD
Pediatric Pulmonary Center Nutrition Trainee

Nutrition is important for growth, development, and lung health. When you have CF, you need extra calories because you burn more when breathing, exercising, and recovering from illness. You also lose some calories through malabsorption, even when taking pancreatic enzymes. Without enough calories, you won't be able to reach and maintain a body mass index (BMI) at the 50th % which is recommended to keep lungs healthy and strong.

There are many ways to increase calories. You can do this by eating more often (3 meals and 3-4 snacks daily), increasing portion sizes (take a few extra bites at each meal), and choosing higher calorie versions of your favorite foods (bagel instead of bread, sports bar instead of a granola bar). You can also add healthy sources of fat to your diet since fat has the most calories in the smallest portion. Finally, make sure to read the "Nutrition Facts Label" to choose the highest calorie foods.

Tips include:

- Add dry milk powder to milk, pudding, oatmeal, baby food, casseroles, and dips
- Drizzle oil over vegetables, eggs, pastas
- Mix ground flaxseed powder into baking mixes, smoothies
- Make pudding, oatmeal, cocoa, smoothies and cream soup with heavy cream or half and half
- Have trail mix for a snack - make with nuts, seeds, chocolate chips, dried fruit
- Sprinkle nuts over ice cream
- Dip veggies and chips in guacamole, bean dip, sour cream dips, or cream cheese
- Add avocado, dressing, mayo, or butter to sandwiches
- Put nut butter or cream cheese dip on fruit
- Spread Nutella and nut butter on a bagel
- Add granola, dried fruit, nuts, and chocolate chips to yogurt and snack mixes

Two great resources for more high calorie recipes are:

http://www.chef4cf.com

http://www.kidshealth.org

Bacon, Egg, and Cheese Breakfast Sandwiches

Note: Pancake rings are a helpful tool to get eggs to be the size of the bagel. You can also microwave the eggs in a small round dish.

4 extra large eggs

4 bagels (more calories than English muffins or bread)

4 slices cheese

4 slices ham or bacon

6 Tbsp butter, divided

Melt 2 Tbsp butter in a large skillet. Place 4 pancake rings in the pan and heat over medium heat.

Add an egg to each pancake ring and cover pan. Cook for 4 minutes or until eggs are mostly set. Remove pancake rings.

Lightly toast bagels and butter each with 1 Tbsp of butter.

Assemble sandwich with one egg, one slice of cheese, and one slice of bacon or ham.

Nutritional Information:

Servings: 4
Calories: 625 (versus 300-350 for a typical breakfast sandwich)

Annual CF Blood Draws

By Erin Seffrood, MS, RD, CSP, CD

You are probably used to getting your blood drawn at least once a year (perhaps more often). Unless you are preparing for your Oral Glucose Tolerance Test (OGTT), you probably come after eating a meal and taking your vitamins. We are learning, however, that the best way to get an accurate picture of your vitamin levels is to have them drawn when you are fasting. That means not eating or drinking anything (except water) for at least 8-12 hours before the lab draw. While you have to be fasting for the OGTT, this may be hard if you are not preparing for this test. Therefore, we recommend that you do not take your CF vitamins on the day you come to clinic. This will tell us if we are giving you the best dose to keep you healthy.

If you wish to get annual labs drawn fasting, you can either schedule a morning appointment or get orders to have the labs done at your local clinic. Simply tell your medical team what your wishes are.