

Cystic Fibrosis Center Quarterly Newsletter

Quality Improvement: Lung Transplant

Our Quality Improvement (QI) team has worked together with many other Cystic Fibrosis (CF) Centers across the nation for the CF Foundation's CF Lung Transplant Transition Regional Dissemination Network (LTT RDN). We joined this initiative to improve our lung transplant referral process. This initiative found that early education regarding lung transplant leads to improved understanding in order for you and your family to make informed decisions about this topic. Our QI team has chosen to provide the CF Foundation's lung transplant "The Journey through Lung Transplant" handout to all patients twelve and above and to those who are interested in learning more about lung transplants.

Even though many patients are not yet ready to take the lung transplant journey, our team has found it important to educate our patients and families earlier, and be available for any questions regarding lung transplants. If you have any further questions regarding lung transplants, feel free to discuss with your child's physician at the next scheduled CF Center visit.

Do you know what your level of activity is?

The cold winter months have kept many of us indoors and less active. Now is a great time to reassess your current physical activity! One tool to measure your level of activity is the Godin Leisure Time Questionnaire (enclosed for your convenience). This is the scale your physical therapist may use to help understand how active you are. Feel free to take a look at the sample activities and score yourself. If you need more activity, our physical therapists recommend trying 15 minutes or more of light or moderate activity 1-2 times a



day and gradually increase.

Welcome to Dr. Chittivelu!

As many of you may know, we said goodbye to one of our longtime adult physicians, Dr. William Tillis. However, we would like to give a warm welcome back to Dr. Subramanyam Chittivelu as one of our physicians in the Cystic Fibrosis Center. Dr. Chittivelu has been in Peoria for 19 years and has had close to 25 years of experience with Cystic Fibrosis patients. He is a professor and director for Pulmonary and Critical Care Medicine Program. He also works closely with the Cystic Fibrosis research team to help gather data for Cystic Fibrosis research. Some fun facts about Dr. Chittivelu include: he loves to play tennis, cricket and watch movies. He is also interested in reading and understanding the Bible.

Please join us in welcoming Dr. Chittivelu!

Family Advisory Board

If you would like to have something discussed at the next quarterly Family Advisory Board meeting, please contact Tricia Green at (309) 624-9634.



Battling Food Insecurity

The topic of food insecurity was given attention during the 2019 North American Cystic Fibrosis Conference. Food insecurity is the lack of consistent access to enough affordable, nutritious food. The CF Foundation recognizes that people with CF often have more than one risk factor for food insecurity and has developed a committee to help the CF community understand this issue and address the problem.

According to the World Health Organization, food has a major role in health, functioning and quality of life. People may experience food insecurity due to a lack of funds and/or transportation to grocery stores and food markets to obtain nutritious foods. Food insecurity is wide-spread and can be linked to stress, depression, anxiety, limited activities, illness, health provider visits, not taking medications in order to save money, etc.

CF Foundation Compass is a personalized, one-on-one service that provides help with insurance, financial, legal, and other issues faced by people with CF, their family, and caregivers. According to the CF Foundation Compass data, “food insecurity is only one of the many financial concerns people with CF may have, such as paying for housing, transportation, utilities, medication and medical bills. The hospitalizations that often come with CF may mean less money coming in, adding to the financial stress.”

Those with CF face many challenges that can make it difficult to battle food insecurity. Cystic fibrosis patients generally require higher calories and more nutritious meals in comparison to what local and state food programs are able to provide. Insurance coverage can be limited for

high-calorie shakes and CF multivitamins. The time needed for treatments can leave less time to plan and prepare nutritious meals.

HELPFUL RESOURCES

Despite the federal, state and local programs, many individuals with CF may still experience food insecurity. Below are a few resources we would like you to be aware of and may help you obtain nutritious foods and snacks to help you or your child maintain optimal nutrition.

- CF Foundation Compass: (844) 266-7277 or cff.org/Assistance-Services/Compass-Service-Request/
- Feeding America - directory of food banks feedingamerica.org/find-your-local-foodbank
- School meal programs can help provide meals at school for your child
- Check with your insurance company to see if they offer any assistance or benefits

ASSISTANCE PROGRAMS

Each enzyme company has its own assistance program for people with private insurance. These programs help with monthly multivitamins, oral supplements, co-pay coverage, and may also have some customer service liaisons to help with insurance coverage.

- Creon Care Forward: (855)227-3493 or creon.com/cfcareforward
- Zenpep Live to Thrive: (888) 936-7371 or live2thrive.org/
- Pertzye Chiesi Care Direct: (888) 865-1222 or pertzycare.com/
- Pancreaze Advantage Program: (888) 998-4887 or pancreazeadvantage.com/

HEALTHWELL

All people with CF are eligible to apply for both the HealthWell Cystic Fibrosis Treatments and the Cystic Fibrosis Vitamins and Supplements grant. For more information, please call (800) 675-8416 or visit healthwellfoundation.org/patients/apply/.

Please feel free to contact the CF Center with any questions in obtaining more information on applying for any of the above programs.

Shamrock Shake Saint Patrick's Day Recipe

Would you like to make your very own shake that will taste just like the famous McDonald's Shamrock Shake? Below you can find a quick recipe to excite your taste buds. After enjoying this yummy shake, you will be able to frolic around with joy, just like our favorite St. Patty's Day leprechauns.

INGREDIENTS:

3 cups vanilla ice cream

1 cup whole milk

1/4 teaspoon mint extract (not peppermint)

9 drops food coloring (green)

Green sprinkles or green sanding sugar

Maraschino cherries

DIRECTIONS:

1. Mix the ice cream, milk, extract and food coloring in your blender on high setting.
2. Top with a generous amount of whipped cream.
3. Sprinkle green sprinkles/sanding sugar.
4. Add the cherry on top.
5. Enjoy!

*Options: Add a half packet of vanilla Scandishake to your milk or substitute milk with vanilla oral supplement (such as Ensure, Pediasure, Kate Farms, Orgain, Boost, etc.) to add more calories.

NUTRITION FACTS:

Serving Size: 1-1 ½ cups

Servings per Recipe: 3

Calories: 323 calories

Total Fat: 17 grams

Sodium: 140 mg

Total Carbohydrate: 35 grams

Protein: 7 grams

Recipe adapted from:
dinnerthendessert.com/mcdonalds-shamrock-shake/



Research Updates

Here are the most recent updates for our CF research at OSF HealthCare/CHOI CF Center.

PROMISE STUDY

Our site has been involved in the PROMISE-OB-18 trial. At this time, we have successfully enrolled five subjects into the trial. This observational study will measure the effects of triple-combination therapy, elexacaftor/tezacaftor/ivacaftor, in people with CF. These drugs are intended to help CFTR protein function closer to normal and will look at how treatment with triple-combination therapy affects people with CF across many different aspects of the disease. This study enrolled both subjects who are heterozygous for F508del mutation (have one F508del mutation and another minimal functioning mutation) and homozygous for F508del mutation (have two F508del mutations). The study has six visits over two years.

SIMPLIFY STUDY

Our site has been selected to participate in the SIMPLIFY-IP-19 study. More to come about that in the near future.

