

Cystic Fibrosis Center Newsletter

COVID-19 Vaccinations

The CF Foundation strongly supports the use of COVID-19 vaccine products by Pfizer-BioNTech and Moderna. These are expected to be available for people who are 16 and older and have underlying health conditions that might put them at increased risk for serious complications from COVID-19 infection, including CF. The Foundation continues to advocate for priority access to vaccines for those with Cystic Fibrosis.

I'M INTERESTED IN THE COVID-19 VACCINE. WHAT SHOULD I DO?

OSF Cystic Fibrosis Clinic is not able to dispense vaccines. Check with your local health department or the health department for the county in which you work for your vaccine eligibility. You may also be able to get the vaccine through your workplace or local pharmacy.

Please call the CF clinic and leave a message letting us know the date you got the vaccine.

Trikafta Expanded Coverage

Vertex, who makes the CF modulator Trikafta, has applied to expand eligibility of this medicine to include children ages 6-11 years old with cystic fibrosis who have at least one F508del or a mutation in the CFTR gene that responds to Trikafta. The FDA has granted priority review of the application and we can expect a decision by June 8, 2021.



OSF MyChart

Reminder to sign up for OSF MyChart. This allows us to give you the option of video visits, if appropriate, for your health and safety. Due to Healthcare Information Privacy Act, we are not able to use other platforms for video visit and you must be a registered user to access OSF MyChart.



Clinic Safety and COVID-19

Now that a vaccine is available, the CF Foundation is encouraging a move back to face to face or in person care as much as possible. The Foundation will give centers credit for one video encounter yearly for each patient. The expectation is that the majority of CF care be done in the clinic setting. To provide the best care, we still need to get yearly labs, blood work and sputum cultures (something that is not a part of video visits).

WE ARE COMMITTED TO PROVIDING SAFE AND EFFECTIVE CF CARE. HERE ARE SOME OF THE WAYS WE WORK TO KEEP STAFF AND PATIENTS/FAMILIES SAFE DURING FACE TO FACE VISIT.

- CF staff has received COVID-19 vaccines
- Patients and families register by phone from CF clinic room instead of waiting in line at registration
- CF staff wears extra protective gear (face shield/goggles and masks) in addition to the gowns and gloves you are used to seeing
- Patients are phone screened for COVID-19 symptoms prior to in person visits
- Patients and families wear masks during visit when clinic staff are in the room with them

Medication Refills

CF clinic often gets notifications from pharmacies that they are unable to get in touch with our families about refills and prescriptions. Often, by the time the pharmacy has contacted CF clinic, they have stopped trying to reach patients and families. We know that timely access to medication and treatments is essential for our patients to

thrive with CF.

We need you to partner with us to improve this situation. Clinic staff often devote a lot a time behind the scenes working with insurance companies to get medications approved and covered. When pharmacies stop trying to reach families, the clinic often has to start the prior authorization process all over again because a new order for the medication must be sent.

Here is how you can help

- Answer phone calls from pharmacies as often as possible. Consider adding their phone number to your contacts so it is easy to tell if this is a legitimate business and not a telemarketing call.
- Make sure your voice mail box is not full so pharmacies can leave messages.
- Include your first and last name in the voicemail greeting so pharmacies will leave you a message.
- Do your best to turn calls from pharmacies on the same day.

Home spirometry

Thank you to the Cystic Fibrosis Foundation for purchasing all of our home Spirometry units. The foundation's ongoing support has created a new method for how we obtain and share lung function data.

We would like to thank all of our patients, parents and caregivers who have agreed to participate in this program. Each unit will specifically be set up for you. Your Cystic Fibrosis team is in the process of getting every patient, who has received their home Spirometry unit, set up properly. This will allow patient to complete Spirometry testing with or without coaching and share data with our CF Center dashboard.

Everyone, who has consented to Zephyrx Spirometry, should have received their home spirometry unit in the mail in addition a handout on how to set up, trouble shoot and clean equipment.

It is important that each patient is familiar with this software program in order to perform quality tests.

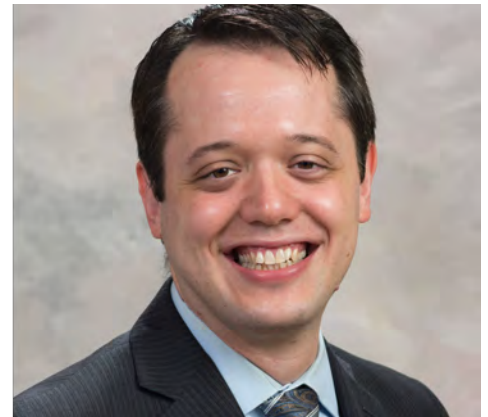
The Zephyrx home spirometry gives your doctor additional information to provide the best care.

Your respiratory therapist monitors the provider dash board and compares your in clinic data with your home Spirometry unit.

If you do not have access to a smart phone or tablet for the Zephyrx home spirometry unit, we do have a few units that may fit your needs. For additional information please speak with your Respiratory Therapist (309) 624-5102.

If you need assistance setting up your Zephyrx home Spirometry unit, please contact your Respiratory Therapist.

Your willingness to participate in this program has given us valuable data to provide the best care during COVID-19 pandemic.



- Hobbies and interests

Hobbies include esoteric board game enthusiast, leisure runner, so I can then eat my amateur chef creations or my wife's baking.

Welcome to a new adult provider

Dr. Joseph Mackey has joined the CF clinic as an adult physician. We are excited to have him as part of our team.

Dr. Mackey went to medical school at University of Kansas School Of Medicine. He completed his residency here in Peoria through the University of Illinois College of Medicine.

In addition to helping with CF, Dr. Mackey works as an Academic Hospitalist for OSF Saint Francis Medical Center and Children's Hospital of Illinois. He is also an Assistant Professor of Clinical Pediatrics and Internal Medicine at the University of Illinois College of Medicine-Peoria. He teaches Quality Improvement processes and Evidence Based Medicine practices to medical students and residents.

- Why I want to work with CF patients

Over the years, I have come to realize that CF is not just a medical diagnosis to be treated, but each patient is a complex person needing support, training and ongoing partnership in navigating the complex layers of care required to stay happy and healthy with CF.

My hope is to help bridge the separations between pediatric patients moving into the internal medicine world, but also the inpatient to outpatient care divide.



Nurition Facts: 73 calories; protein 2.9g; carbohydrates 7.2g; fat 4.5g; cholesterol 2.7mg; sodium 11.2mg.

Recipe source: Allrecipes.com

Spring Recipe

Grilled Asparagus with Lime

1 teaspoon butter

1 tablespoon olive oil

1 clove garlic, minced

1 medium shallot, minced

1 bunch fresh asparagus spears, trimmed

¼ lime, juiced

salt and pepper to taste

Directions

1. Melt butter with olive oil in a large skillet over medium heat.
2. Stir in garlic and shallots, and cook for 1 to 2 minutes.
3. Stir in asparagus spears; cook until tender, about 5 minutes.
4. Squeeze lime over hot asparagus, and season with salt and pepper.