

Cystic Fibrosis Center Newsletter

Reminders

Yearly Labs

Please make sure to complete your yearly labs. Summer is a great time to take care of this so you don't have to work around school schedules.

You can visit any OSF outpatient facility that draws blood or come to the hospital for these tests.

Be prepared to tell the lab exactly what orders you need drawn so things are not missed. Here is the list you will need to share with the lab.

CMP

CBC

IGE level

Vit A, E, D

If over 10 yrs old, you will need to get your Oral Glucose Tolerance Test if you have not been diagnosed with CF Related Diabetes.

New Equipment

When you get new home medical equipment, keep paperwork with date purchased/received along with name of the medical supply company that provided it.

It helps to mark the date you received equipment (nebulizer, vest, etc.) on the item using permanent marker. This will help you know how old your equipment is and help get replacements in a timely manner. For example, you are eligible for a new nebulizer machine after 5 yrs.

Medication Refills

Please check with your pharmacy if you need a refill on your medication. If you notice on the bottle there are no remaining refills, please contact the clinic so we may send a new prescription with refills. Allow enough time in the event a prior auth is needed by your insurance for the medication. Thank you!

Summer Travel

If you are traveling this summer and need a note to travel with your medication and equipment, please contact the clinic 2 weeks prior to your trip.

Clinic Closed

Clinic will be closed in observance of Memorial Day May 27th.

Modulators

Remember to get yearly labs if you are on a modulator. We need these to get insurance approval for refills.

If you just started a modulator medication, you will need labs every 3 months for the first year. If under 18 and taking a modulator, eye exams are needed every 1-2 years.

Spring Cleaning

Spring is a great time to make sure things are up to date with your CF medications and equipment. Please turn on any equipment you have not used in more than 1 month to make sure it still works. Try on your vest to make sure it still fits, if you have not been using it regularly.

Appointment Reminders

Please be aware there have been changes to the OSF text alert system for appointment reminders. You will no longer receive text message communications from OSF until you opt into the new system. This can be done by texting "START" to 90373, by utilizing your communication preferences on your OSF MyChart app, or by requesting this at the registration desk at your next appointment. "

New Provider

Welcome to Bobby Lucia, DNP, APRN-FPA, FNP-BC, LCPC . He will be seeing pediatric patients. Bobby works at Bradley University teaching nurses who are pursuing a doctoral degree. He also sees patients in Pediatric Pulmonary Office for pulmonology and sleep a couple days per week and works as needed at the Heartland after hours clinic. Bobby and his wife have a son and three dogs. He describes himself as an “avid lover of all cheese”.

We are excited to have Bobby as part of the CF team.

Fat Containing Foods for Modulators

Tired of eating the same foods over and over with your Trikafta/Orkambi?

Here are some new ideas

- Balance Breaks® nut and cheese snacks
- SeaPoint Farms dry roasted edamame (available on amazon)
- Rx Bar® almond butter squeeze
- Snickers® High Protein Bar
- Kodiak® Protein Balls mix

