

Cystic Fibrosis Center Newsletter

Warm weather reminder

Don't forget to hydrate as you head outside now that the weather is warming up. You need to replace lost fluids AND salt when you exercise or spend a long time outside during hot weather.

Here are some signs that you need to replace sodium :

Fatigue Weakness
Irritability Headache
Muscle spasms/cramps
Light headed
Nausea/vomiting

If you experience any of the above during or after exercise or spending time outside when it is hot, make sure to hydrate with a sports drink/electrolyte replacement like Gatorade® instead of water.

Kroger Specialty Pharmacy

Kroger Specialty Pharmacy is no longer supplying Cystic Fibrosis meds or products (high calorie shakes/bars). If you have used them in the past and are having trouble getting meds or shakes refilled, please give clinic a call.

Vaccine Boosters

Your CF team recommends COVID vaccination for all individuals age 5 and up. It is particularly important for those with cystic fibrosis to protect against severe COVID disease. In addition, booster doses are recommended for everyone 12 and up according to the following guidelines:

https://www.cdc.gov/coronavirus/2019-ncov/vaccines/booster-shot.html?s_cid=11737:cdc%20covid%20booster%20shot%20guidelines:sem.ga:p:RG:GM:gen:PTN:FY22



Medication Prior authorizations

There is quite a bit of paperwork behind the scenes to get your Cystic Fibrosis medications to you. Insurance companies require Prior Authorization for ALL CF meds. To complete a Prior Auth, we have to send in copies of clinic notes and labs. If you haven't completed yearly labs or been seen in CF clinic in the last 3 months and you don't have an upcoming appointment scheduled, please call the clinic.

Family Night Presentation

Did you miss family night on November 17, 2021? You can still watch a recording of the event by going to the OSF CF Center website
<<https://www.osfhealthcare.org/childrens/services/pulmonology/cystic-fibrosis/>>.

Clinic visit prize

Starting in April, our next health promotion prize for attending your clinic visits for the quarter is a yoga ball/exercise ball! The Physical Therapists will be handing out Exercise Balls with age specific programs to get you started with being creative and developing fun activities you can do at home. The activities can assist with strengthening, stretching, airway clearance, and, improving mental health. We hope you enjoy this Exercise Ball adventure!

Staff changes at clinic

Dear CF Families,

As many of you know, Dr Mohannad Mannaa, one of our pediatrics physicians, is leaving OSF for another opportunity. While this is sad news for our CF team, we thank Dr. Mannaa for his important role in our CF center and we wish him well in his future endeavors. He will be missed!

Beginning in May, Dr. Jeff Benson, one of our pediatric pulmonologists, will be joining the Pediatric CF team. Please help us in welcoming Dr. Benson! UICOMP and the Children's Hospital are also actively recruiting additional pulmonology physicians.

Please let us know if you have any questions about this transition,

Heather McLauchlan, MD
Center Director

Home Spirometry

The ZEPHYRX home Spirometer for PFT, app has been updated.

The new and improved software update allows for remote monitoring and real time coached video spirometry testing and independent testing.

Our goal is to continue providing quality in person and video visits.

If you have not used your spiro unit in the last 6 months, follow the steps below to get started:

1. Please download the Breath Easy app. On to your Android or IOS phone/tablet
2. Check the batteries in your Spiro Bank Smart Spirometer
3. If your unit does not connect to the program remove/or replace the batteries
4. The app will perform a search, the last 4 digits of your Spiro unit will display to connect the units
5. Update your health demographics with the most recent height and weight
6. If the heart in the right upper corner is not white, click on the heart to consent to share your data with your CF center.
7. Please choose OSF Health care Pediatric or Adult program.
8. Review breathing techniques
9. When you are ready, click the continue button, place the mouth piece in between your teeth, lips are tightly seal around the mouth piece, try not to put your tongue in the middle. Take a deep breath in, blast out fast and long then take breathe back in.

You are required to complete a minimal 3 trials, the max number of 8 trials.

- After 3 tests, if you meet the criteria you will be given the option to end the session.
- If you complete 8 trial the sessions, data will automatically upload to our provider dash board when end that sessions.

Practice any of the Breathing exercises to improve your Spirometry breathing technique.

If you have any questions please contact your Respiratory Therapist 309-624-5012

