

# CF Connection

Winter 2021

University of Florida Adult Cystic Fibrosis Center

## COVID Updates

We recommend getting the COVID vaccine as soon as it is available. If you've had a lung transplant, discuss getting the vaccine with your transplant team. For the latest information about the COVID vaccine from the CF Foundation, please click [here](#) or [www.cff.org](http://www.cff.org).

On Thursday, January 14<sup>th</sup> from 7-8 pm EST, the CF Foundation will host a virtual town hall. A panel of experts will share the latest on COVID-19 vaccines and answer questions from the community. Click [here](#) (or visit [www.cff.org](http://www.cff.org)) to register and submit questions for the panel.

### Continued Wellness During COVID-19

The CF team continues to be available to help support you during this challenging time. Dr. Fedele, the clinical psychologist on our pediatric team, recently gave a talk on self-care strategies for families of people with CF as part of the CF Foundation's Family Education Day. You can watch his 30-minute presentation at <https://tinyurl.com/y3hdwvqk>

These wellness-related apps might also be helpful:

**Mood Kit** uses cognitive behavioral therapy to address mood issues, with daily activities to help boost your mood, a thought checker to help you ID and modify negative thoughts, a mood tracker to monitor your progress over time, and an online journal to record your thoughts.

**Breathe2Relax** teaches you how to use breathing to relax

**Calm** This app offers 3 to 25 minute practices that focus on anxiety, stress, focus and more.

**SAM** Self Help for Anxiety Management helps you understand and manage anxiety through self-help exercise and private reflection.

**MindShift CBT** uses strategies based on Cognitive Behavioral Therapy (CBT) to help you learn to relax and be mindful, develop more effective ways of thinking, and take charge of your anxiety.

**Take a Chill** helps you bring mindful practices into a daily routine using quick mindful exercises and thoughtful activities.

**Aura** has thousands of meditations for stress, anxiety, sleep, and more - personalized just for you. Aura gives you instant, unlimited access to meditations, life coaching, and stories from top coaches and therapists around the world.

**Smiling Mind** offers meditations to help you find inner peace. It offers kid-friendly meditations, an option to bookmark favorites, and charts to track your progress.

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## We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Please send e-mail to [Jennifer.Hillan@medicine.ufl.edu](mailto:Jennifer.Hillan@medicine.ufl.edu).

## Trikafta News

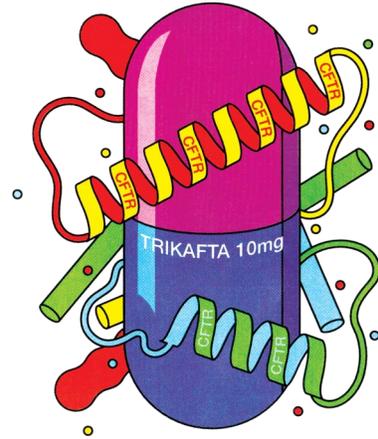
More people are now approved for the modifier drug Trikafta! People with CF who are 12 and older and who have one copy of the F508del gene or one of the newly approved mutations are eligible for treatment with Trikafta. To see if you are eligible, visit <https://www.trikafta.com/who-trikafta-is-for>. This brochure has more information about Trikafta: <https://www.trikaftahcp.com/sites/default/files/patient-brochure.pdf>.

If you are using Trikafta, it's very important to get lab tests every three months for the first year to be sure Trikafta isn't damaging your liver. After one year of treatment, you'll get your labs twice a year. Insurance companies require you to have regular lab work and regular visits with your CF care team to continue paying for Trikafta. After starting Trikafta, it's important not to make any changes to your other medications without talking to your CF care team first.

Many people gain weight after starting Trikafta and although we know this is a good thing, it does come with new challenges. After a lifetime of being encouraged to eat as many high-fat, high-calorie foods as possible, now it's important to make healthier food choices and increase physical activity. It's also important to learn to accept your new body, since society tells us that skinny is good. Please talk to your CF team about your concerns. We are here to help!

Read about how these adults with CF managed their weight gain after Trikafta:

<https://www.cff.org/CF-Community-Blog/Posts/2020/How-I-Found-Acceptance-for-My-Trikafta-Weight-Gain/>  
<https://cystic-fibrosis.com/living/trikafta-weight-gain/>  
<https://www.cfwarriorproject.org/the-trikafta-gain/>



## Welcome Carolyn Ascencios!



Please help us welcome our new social worker Carolyn to the team! Carolyn is a licensed clinical counselor and comes to us with over 20 years of experience. She is excited to meet you in clinic! She can provide you with emotional support and connect you to community resources to help you improve your quality of life. She is a Florida native and in her spare time, Carolyn enjoys hiking and canoeing and playing with her two bearded collies.

## Physical Therapy for People with CF



Exercise is an important and FUN part of your daily routine that can help you stay healthy and enjoy your favorite activities. We are excited that UF has physical therapists who can work with you and help you be more active! A physical therapist (PT) can:

- ✓ Help you design a daily fitness program.
- ✓ Help you find ways to maintain good posture, manage pain, and build or regain muscle strength, endurance, and flexibility.
- ✓ Teach you how exercise can be an important part of daily airway clearance.
- ✓ Help make a plan for any of your specific concerns.

A comprehensive approach by exercise specialists is the safest and most effective way for people with CF to become more physically active. This includes exercise testing, program development, and tracking progress. Our CF team can arrange a PT Evaluation appointment for the same day as your CF clinic visit. We may recommend an evaluation at your clinic visit or you can also request one by contacting us anytime.

For more information about exercise and CF:

Day to Day Exercise and CF

<https://www.cff.org/Life-With-CF/Daily-Life/Fitness-and-Nutrition/Fitness/Day-to-Day-Exercise-and-CF.pdf>

Creating a Fitness Plan that Works for You

<https://www.cff.org/Life-With-CF/Daily-Life/Fitness-and-Nutrition/Fitness/Creating-a-Fitness-Plan-That-Works-for-You/>

## Home Spirometers

If you don't have a home PFT device, please let us know and we can get one for you. If you already have one, be sure to set it up and start using it! This is a wonderful way to monitor your lung function between visits or for telemedicine visits.

Please let us know if you need any assistance. Our respiratory therapist Tracy Tanner will be happy to help you. Once you've got your device set up and you are using it, you can email your pft report to [homepftreport@medicine.ufl.edu](mailto:homepftreport@medicine.ufl.edu).

### Flu Vaccine – It's Not Too Late!

The CFF and your care team highly recommend the annual flu vaccine. Flu season goes through March so if you haven't already gotten your flu vaccine, go get it!

# CF Connection—UF Cystic Fibrosis Center

## Is it time for a Colonoscopy?

The risk for colon cancer is 5-10 times greater for people with CF than those without CF. People who have had a lung transplant have 20 times higher risk. Because of this increased risk, the CF Foundation recommends **people with CF get a colonoscopy at age 40. People with CF who've had a transplant should get it done at age 30** (depending on age of person at transplant).

Symptoms of colon cancer may include blood in stools, weight loss, stomach pain, or sudden changes in bowel movements. **Many people with colon cancer have no symptoms at all**, which is why screening with a colonoscopy is so important. Most colon cancers start with polyps (small, abnormal growths of tissue in the lining of the colon or rectum). A colonoscopy can detect polyps so they can be removed before they turn into cancer.

For more information about colon cancer and how to prepare for a colonoscopy, please click [here](#).

## Sample a Smoothie

A smoothie full of fruits and veggies is an easy way to get important nutrients for good health. And it's a delicious meal or snack that is great when you are on the go! Start with some frozen fruit (think frozen berries, bananas, or whatever you like best). Then add fresh fruits or veggies (maybe half of an avocado for some healthy fat), followed by your liquid, such as cow's milk (or milk alternatives such as almond or coconut milk), juice, or try kefir (a good source of probiotics for gut health). Last, toss in your add-ins such as peanut butter powder, oats, chia seeds, ground flax seed (whatever you like!). If you are trying to gain weight, be sure you are adding high-calorie foods such as whole-fat milk, whole-fat Greek yogurt, avocados, or nut butters. There are so many ways to make a smoothie – if you need inspiration, check online for easy recipes!



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