

# CF Connection

Fall 2022

University of Florida Adult Cystic Fibrosis Center

## Getting Help From Your Support Circle

First let's define what a support circle is. A support circle is your network of people that can give you practical or emotional support. Your support circle can help you improve your overall health and reduce stress and anxiety.

Mental health can be a tough battle. Sometimes it can take hold of your life and make you feel unworthy of social interactions or being cared for by others. However, it is important to try to work through these thoughts and remember that everyone is worthy of being cared for and loved!

Now let's take a look at who can be the members of your support circle. This can include parents, siblings, extended family members, friends, and community members. It can be hard to ask others to be there for us. But the truth is, sometimes it becomes too emotionally hard to be there for ourselves. We don't want to seem vulnerable, but it's okay to ask for help, even when we aren't sure if we need it. Also remember that it's okay to accept help when it's offered.

A good support circle can give you unprompted check-ins, positive influence, and allow you to talk about your health concerns, or not talk about your health concerns if you'd like a distraction!

So, when to ask for help?

- If you feel like your personality is changing (such as starting to feel withdrawn, sad, depressed, angry, anxious, or moody).
- If you feel like you want to avoid contact with friends and family.
- If you feel like you are not taking care of your personal hygiene (such as not bathing or washing your clothes) or not taking care of your pets or living space.
- If you feel hopeless, overwhelmed, or worthless.



Your support circle is a union with one common goal and that is to make sure that you are emotionally OKAY. Why?! Because they absolutely LOVE you! The weight of the world and your chronic illness can be a lot to handle at times so it's okay to say **"I'm not okay, I need you."** Tell your support circle how they can help you in that moment and what exactly you need them to do. Be specific with your request. This could be anything from a hug, a listening ear, or help with a child so that you can do your treatments or have time for self-care.

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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).

## Medication Updates

Please let your pharmacy know ASAP when you need medication refills/prescriptions. Insurance often requires Prior Authorizations (PAs) for many medications and these take time to complete. To be sure you aren't left without medication, please request a refill from your pharmacy at least two weeks before you run out of your current prescription.

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. If you don't come to clinic visits regularly, we cannot renew your Trikafta Rx.



After starting Trikafta, it's important not to make any changes to your other medications without talking to your CF care team first. If you are a woman taking Trikafta, you have a higher chance of getting pregnant than you did before you started Trikafta. Be sure to use birth control if you don't want to become pregnant. Talk with your care team if you plan to become pregnant so we can discuss all of your medications and help you plan for a safe pregnancy.

## Hurricane Season

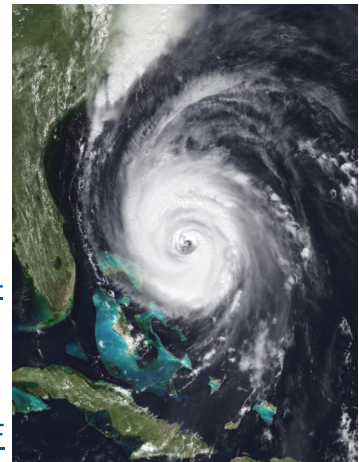
Hurricane season goes thru November. Did you know that the Cystic Fibrosis Foundation has disaster planning resources? Check out the links below:

**Disaster and Emergency Preparedness Planning for People with CF:** <https://www.cff.org/Assistance-Services/How-Compass-Helps-People-With-CF-and-Their-Families/Disaster-and-Emergency-Preparedness-Plan/>

**Tips for People with CF Affected By Natural Disasters:** <https://www.cff.org/Living-with-CF/Navigating-Insurance/Your-Insurance-Plan/Tips-for-People-With-CF-Affected-by-Natural-Disasters.pdf>

**Disaster Preparedness Plan Checklist:** <https://www.cff.org/Assistance-Services/How-Compass-Helps-People-With-CF-and-Their-Families/Disaster-Preparedness-Plan-Checklist.pdf>

**Compass is ready to support people with CF and their families impacted by a hurricane.** Contact Compass at [cdt@cff.org](mailto:cdt@cff.org) or 844-266-7277. Calls related to natural disasters are handled urgently.



## We Need You!

Are you interested in improving care at your CF care center? If so, please join your Adult Cystic Fibrosis Clinic's Patient & Family Advisory Council (PFAC)!

**Who:** Work with other people with CF, their families, and your care team to elevate your care, address your concerns and improve your overall experience.

**What:** Patient Advisory Councils help their local care center understand what it is like to receive care, identify opportunities for improvement in the system, help test innovations, and create tools and resources that benefit all CF patients.

**Where:** We host our meetings via Zoom.

**Meeting URL:** <https://ufl.zoom.us/j/9675925101>      **Meeting ID:** 967 592 5101

**When:** The first Thursday of the month for 30 minutes starting Sept 1 @ 5:30 pm EDT. There is no long-term commitment necessary.

If you are interested in learning more about the PFAC please chat with us the next time you are in clinic, send a MyChart message, or join the zoom link above on the first Thursday of the month at 5:30 pm EDT.

## PFT Update

If you have your home PFT device, 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. This will also greatly reduce your wait time in clinic if you bring your device with you! We often get backlogged in the PFT room and if you have your device, you can do your own PFTs in your clinic room. Another way to reduce your wait time at clinic is to check in with the front desk staff rather than using the kiosk.



Please let us know if you need any assistance using your device. Our respiratory therapist Tracy Tanner will be happy to help. 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) or upload to a MyChart message.

If you want a copy of your PFT report that was done in clinic, you can get it from Medical Records after your doctor has interpreted it (usually a couple of days). Call Medical Records at 352-265-0131.

## Flu Season—It's Right Around the Corner!

The CFF and your care team highly recommend the annual flu vaccine for people with CF and their families. Flu season is from October thru March. Yes, you can get both the flu AND COVID but you can help prevent it by getting your flu shot when it's available!

# CF Connection—UF Cystic Fibrosis Center

## Get Involved!

Check out the upcoming CF Foundation virtual and in-person events. Visit <https://www.cff.org/get-involved> for more info.

### October 1 – Siesta Key – Great Strides Walk

### October 5 – Ponte Vedra Beach – Oldest City Red Trout Classic

Join us for this year's exciting fishing tournament starting from the docks of Ponte Vedra Beach! Guests will enjoy two days of amazing fishing for redfish and trout, guided by local professional captains. The event features a captains party, happy hour, an awards celebration and silent, live and Bid for A Cure auctions.

### October 21-22 – CF FamilyCon

CF FamilyCon is a free, two-day virtual event for adults with cystic fibrosis, their families, and friends a space to connect, share, and learn from each other.

### November 12 – Tampa Rock n Roses

Our Rock N' Roses event will bring the Tampa Bay community together to support a great cause - the fight against cystic fibrosis. We will honor the work done thus far in the fight, and those who have contributed to the success of the Foundation's mission. Join us for a night of food and drinks from local vendors, live music, a silent and live auction, and plenty of fun!

### November 13 – Deland – Cycle for Life

Our 2022 CF Cycle for Life event will feature in-person and virtual experiences to help make a difference for people living with cystic fibrosis. Routes vary from 19 miles to 100 miles.

## BEAM for CF!

**Beam** is an online exercise program for people with CF. They have live and on-demand classes as well as motivational and community support. Their classes support people at all life stages and all fitness levels and their instructors either are trained in CF or live with CF. Classes include exercises to improve breathing and airway clearance, exercises to improve pelvic floor strength to reduce stress incontinence, Pilates, high intensity interval training, yoga, and lots more! Membership is free for people with CF thru the end of 2022. See all that Beam has to offer at <https://beamfeelgood.com/on-demand/cystic-fibrosis>

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