

# CF Connection

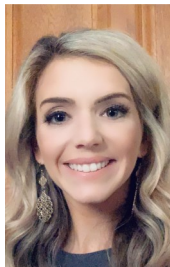
Fall 2021

University of Florida Adult Cystic Fibrosis Center

## Research—WE NEED YOU!

The improvements in life expectancy and quality of life for people with CF have been made possible by research. We cannot get potential new treatments approved without patients in clinical trials. It's important that every person who is able to participate contributes until CF = Cure Found! We are proud of how many trials we've had at UF, and we owe it all to our patients, doctors, and research coordinators. Have you met any of our Coordinators?

**Alexa Smith**, BAS, CCRP has been a Clinical Research Coordinator at UF for over 4 years. Alexa manages the Pediatric CF Clinical Trials, led by Dr. Delgado. Currently, Alexa leads the SIMPLIFY study which tests the safety and tolerability of discontinuing airway clearance medications after taking Trikafta. This study is for patients 12 years and up. A stipend is provided and it's only an extra 3 visits.

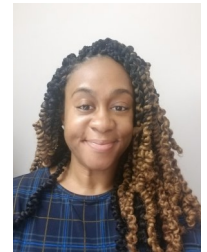


Our team will be opening a new trial called PREDICT and PATIENCE. This study is for patients over the age of 6 years who have nontuberculous mycobacteria (NTM). Patients would need to be willing to discontinue azithromycin. If you are interested in either study, please contact Alexa via mychart or at 352-273-7505

**Sarah Barbey**, MS, CCRP is a pediatric Clinical Research Coordinator and has been with UF for 7 years. Sarah is the regulatory coordinator for the Pediatric CF clinic, supporting Dr. Delgado and Alexa Smith, in running research studies to help improve the lives of patients with CF.



**Noni Graham**, MPH has been a Clinical Research Coordinator with the UF Adult CF Program for 6 years, managing studies led by Drs. Lascano and Trillo-Alvarez. Noni may reach out to you periodically with available studies. Here are a few that are available now:



The CF Foundation's CHEC-OB sweat chloride study welcomes people with CF 4 months of age and older, who use any of the CFTR modulators (Kalydeco, Orkambi, Symdeko, Trikafta). This study has a one-time visit for a sweat chloride test and questionnaire. A stipend will be provided, and previous enrollees who've switched CFTR modulators can participate again!

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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).

## Research (cont.)

Brand New! Aridis Pharmaceuticals is sponsoring a study of AR-501: **inhaled** gallium citrate vs. placebo among those 18 years and up with chronic pseudomonas aeruginosa and FEV1 of at least 45%. If you meet the study criteria, there are 3 weekly doses with close observation for up to 24-48 hours after each dose. There are 12 visits, and total time on study is **6 weeks**. Stipends, hotel and mileage reimbursements provided.

We have another study for people with CF 18 years and up with chronic pseudomonas aeruginosa and 40-90% FEV1. When you have an infection, an enzyme called arginase is produced that damages CFTR and decreases nitric oxide in the lungs. Low nitric oxide interferes with proper lung functioning, and can lower the body's ability to fight infections. Calithera Biosciences has developed a **twice daily pill therapy** that may work to correct nitric oxide deficiency, improving the body's ability to fight infections, and improving lung function. This study tests for the safety and tolerability of this medication in people with CF. There will be 5 weekly visits, for a total of **28 days** on study. Stipends, hotel and mileage reimbursements provided.

If you are interested in the above studies, contact Noni via mychart or at 352-294-5195. If none of these studies are a good fit, no worries! Reach out to any of our coordinators for more information, and visit this link: <https://Pulmonary.medicine.ufl.edu/research-1/clinical-trials/cystic-fibrosis-cf/> to learn about new opportunities on the way.

Also, consider becoming a volunteer with Community Voice. People living with CF and their families know CF better than anyone. Community Voice is an opportunity to make an impact by partnering with the CF Foundation to bring your insights and priorities to the forefront of CF research, care, and programs. Share your opinions through online surveys, focus groups, committees, and more! To join, email [communityvoice@cff.org](mailto:communityvoice@cff.org) or visit [www.cff.org/CommunityVoice](http://www.cff.org/CommunityVoice)

## 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.



## COVID Resources

We recommend everyone who is eligible for the COVID vaccine go and get it if you haven't already. To find a vaccine site near you, you can text your zip code to **438829** (GET VAX, in Spanish at 822862) or visit [vaccines.gov](https://www.vaccines.gov). You can also call 800-232-0233 to speak with someone who can help you find a vaccine site. COVID vaccines are also available at the Medical Plaza Pharmacy on the first floor of the Medical Plaza on Mondays, Wednesdays, and Fridays. We also recommend getting the 3rd booster shot when it is available. If you are post-transplant, you can get the booster shot 28 days after your 2nd vaccine shot and it is available now. If you are not post-transplant, you can get your booster shot this fall (possibly starting Sept 20 according to CDC), as long as it is 8 months after the date of your 2nd vaccine shot.

If you have symptoms of COVID (fever, increased cough, shortness of breath), we recommend that you get tested as soon as possible. If you are positive or have a known exposure, we recommend starting monoclonal antibody therapy (Regeneron), which can help prevent severe symptoms. This therapy should be started as soon as possible (no more than 5 days) after testing positive/known exposure. In clinical trials, this treatment resulted in a 70% reduction in risk for hospitalization and death, and an 82% reduction in risk for contracting COVID-19 for people who were exposed to the virus by members of their household. To find a COVID testing site or a monoclonal antibody treatment site near you, or to learn more about monoclonal antibody therapy, please visit [Florida COVID-19 Testing Sites | Florida Department of Health COVID-19 Outbreak \(floridahealthcovid19.gov\)](https://www.floridahealth.gov/covid-19/testing-sites).

If you have any questions about COVID, including vaccines, mask-wearing, school, clinic visits, and staying safe, the CF Foundation has TONS of information at [COVID-19 Community Questions and Answers | CF Foundation](https://www.cff.org/covid-19) (www.cff.org)

Do you need help paying your rent or utilities? If you live in Florida and meet income guidelines, you may be eligible for assistance from OUR Florida. Click here to learn more and see if you qualify: [Helping Florida Recover and Rebuild from the COVID-19 Public Health Emergency | Our Florida](https://www.ourflorida.com) (www.ourflorida.com)

Did you know that all Medicaid plans offer expanded benefits that include things like reimbursement for mileage to appointments, meals for long trips, hotel stays, transportation service, and a free smart phone with cell service? Due to the COVID-19 emergency, cell phone benefits have been temporarily expanded to include unlimited minutes, unlimited data, and a 10GB hot spot. To check your eligibility and apply, visit [www.safelinkwireless.com](https://www.safelinkwireless.com). For more benefit details, request to speak with a case manager by calling your insurance's customer service number.



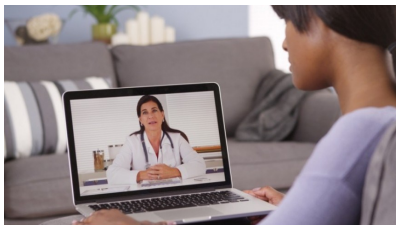
### Flu Season is Right Around the Corner!

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! Stay healthy by getting your flu shot when it's available!

# CF Connection—UF Cystic Fibrosis Center

## Telehealth Visits

We prefer to see you in clinic every three months for a regular visit (as recommended by CFF), but if that is not possible, you can ask to schedule a telehealth visit. All you need for a telehealth visit is a device (phone, laptop, desktop, tablet) and an internet connection. Most telehealth visits are conducted through Zoom or right from your MyUFHealth account. Click the link below to watch videos that will help you prepare for a successful telehealth visit:



[Telehealth Resources for Families - Family Voices.](#)

We would also like you to complete a home spirometry and send results to us through MyChart before your visit. It's also helpful to check your weight, temperature, O2 sat, and pulse on the morning of your appointment if possible.

## Congratulations Dr Trillo!

We are excited to announce that Dr Trillo is our new CF Center Director! Dr Lascano is our CF Center Associate Director and TDN Director.

## Upcoming Events

**Adult Patient and Family Advisory Council Sept 16th @ 12 noon EST**—join us to help improve the quality of care at our clinic! We need your input! Join us on Zoom Meeting ID 962 7181 7523.

**BreatheCon Sept 24-25**—a free, two-day virtual event where adults with CF ages 18 and older come together to discuss their unique experiences through open and honest dialogue, while celebrating the power of community and connection. BreatheCon will provide opportunities for everyone to find a place in the CF community, even if you've felt that you don't belong. BreatheCon will feature keynote panels, group chats, fun activities, and small-group video breakouts on issues that are unique to people living with cystic fibrosis. Come share, connect, and learn while supporting each other and being inspired by one another. For more info, visit <https://www.cff.org/>

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