

# CF Connection

Spring 2021

University of Florida Adult Cystic Fibrosis Center

## Exercising for Good Health

The COVID pandemic has caused many stressors for families which can impact the body, both physically and mentally. Staying physically active every day for at least 60 minutes can provide many benefits. Regular exercise helps the heart so it is stronger during stress. Regular exercise also helps the lung function so there are more reserves to use during severities or lung infections.

### *Why Exercise is Important in Cystic Fibrosis:*

Exercise benefits everyone, but people with cystic fibrosis benefit even more from being physically active because exercise can:

- ✓ slow the rate of decline in lung function, which means people with CF may keep good lung function longer.
- ✓ help clear mucus from the lungs, allowing for easier breathing.
- ✓ create more reserve for the whole body to rely on during periods of lung infection. This means that someone who is fit may be able to resume their activity faster following a bout of illness.

### *What Kind of Exercise to do During the Pandemic?*

If you're worried about possible exposure to COVID, consider completing activities from home, or going to the neighborhood park or trail. Here are a few things to try.

### *Endurance:*

- ✓ Go for walks or runs around the neighborhood or the local park
- ✓ Swim lessons or recreational swimming
- ✓ Cardio classes through YouTube videos



### *Mobility:*

- ✓ Yoga classes through YouTube videos
- ✓ Free online classes from CFYogi (see next page)
- ✓ Shooting a basketball
- ✓ Swinging a baseball bat, golf club, or tennis racquet

### *Core strengthening:*

- ✓ Sit-ups, crunches, and plank pose
- ✓ Pilates by accessing YouTube videos

### *Leg strengthening:*

- ✓ Plyometrics: standing jumps, long jumps, side jumps
- ✓ Squats
- ✓ Obstacle courses

By: Berina Fern, Dietetic Intern

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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).

## Free Online Exercise Classes

**Beam** offers users access to on-demand workouts, live classes, community groups, and special events. The platform connects users with physiotherapists, physical therapists, instructors, and other people living with CF while exercising in recognition that community is an essential component of any well-being program. Classes are led by specialized physical therapists and trainers who are experts in, or in some cases living with, cystic fibrosis.

The CF Foundation has worked with Beam to offer FREE classes to people with CF through 2021. To sign up, visit <https://beamfeelgood.com/home>, click “Get Started” in the upper right-hand corner of Beam’s homepage and navigate through the registration process. Once registration is complete, a pop-up window will appear to confirm that you have been granted free access from the Foundation. No promo code is necessary.

**CF Yogi** - Yoga is a uniquely valuable tool for managing Cystic Fibrosis due to its focus on breathwork and unity of body, mind, and spirit. A regular yoga practice improves strength, balance, and flexibility, and can even improve lung function. It helps give peace of mind by bringing us into the present moment, helping to relieve stress and anxiety. All of us can benefit from the tools that yoga gives us to improve our physical health, mental well-being, and overall quality of life.

CF Yogi offers free yoga classes specific to the needs of the Cystic Fibrosis community. Learn more at <https://Cfyogi.org>



## Welcome Zoe Corcoran!



Zoe Corcoran is our new Program Coordinator Assistant! Zoe moved to Florida from California to attend the University of Florida. She is currently a sophomore, planning to double major in business administration and public health, and in the future she hopes to pursue a master’s degree in hospital administration. She is an active member of UF’s Army ROTC program, and intends to graduate as an officer in the United States Army. After interning at Flagler College over the summer, Zoe developed a strong interest in the administrative side of the medical field, and is excited for the opportunity to work alongside such a capable team while meeting patients and gaining experience and knowledge along the way. When she isn’t studying or working, she enjoys fostering cats from Gainesville’s humane society, and volunteering at local shelter events.

## Upcoming Events & Opportunities

### *Upcoming Virtual Events*

#### **Mental Health & Cystic Fibrosis** – Tuesday April 20<sup>th</sup> at 7 PM EST

The CF Foundation presents a “real and raw conversation around mental health and CF.” The panel includes a new CF mom, and experienced CF mom, and adults with CF. To register, visit [https://afasignup.formstack.com/forms/mental\\_health\\_in\\_cf\\_community\\_event](https://afasignup.formstack.com/forms/mental_health_in_cf_community_event)

#### **ResearchCon** – April 15<sup>th</sup> and 17<sup>th</sup>

Mark your calendars! If you are 16 and older, you're invited to join us for ResearchCon, a free, online educational event. More than 80 researchers, clinicians, and CF community members will share the latest CF research on topics including CFRD, the impact of COVID-19 and telehealth, mental and emotional health, GI and endocrine system, disparities in CF care and experiences among people of color and LGBTQ+, and more. Attendees will have the opportunity to have their CF science-related questions answered by the experts during roundtables and participate in skill-building workshops on how to engage with care teams, overcome daily care obstacles, and navigate insurance. Check out the agenda and register at: <https://cff.swoogo.com/researchcon2021/1018879>

#### **Scholarship Opportunity**

Students with CF who are pursuing an undergraduate or graduate degree in 2021-2022 are eligible to apply for the Abbie CF Scholarship. Winners will be awarded up to \$25,000! Application deadline is April 30<sup>th</sup>. For more info, please visit <https://www.abbiecf scholarship.com/>.



#### **Research Opportunity**

Are you using a CFTR modulator like Kalydeco, Orkambi, Symdeco, or Trikafta? If so, there is a study opportunity for you from the CF Foundation! The study observes changes in sweat chloride after use of any CFTR modulator for at least 90 days. It's a one-time study visit with a sweat test and questionnaire, and uses your latest PFTs and data from the CF Registry. If interested please contact Noni Graham at 352-294-5195 to schedule. We may be able to coordinate your visit before your next clinic appointment. The stipend is \$75. NOTE: You can participate more than once if you ever switch to another modulator.

# CF Connection—UF Cystic Fibrosis Center

## Saving Money on Insurance

I use Florida Blue, but I'm sure other insurance companies do something similar. They have a bunch of informative videos and online tutorials you can do which give you statement credits toward your premiums. For example, my premiums are about \$200 a month, but I spent about 30 minutes watching a few videos and got a \$250 premium credit (so I don't owe anything this month). There are more videos and online tutorials I can do for a maximum of \$500. Since I know insurance concerns and costs could be an issue for many, this is a great and quick way to get free money!! With Florida Blue, the program is called 'Better You Strides'. Check with your insurance company to see if they offer something similar. With Florida Blue, if your premium is less than the credits you earn, they give you a check!

Andrew W., adult with CF

## We Need You!

The reinitiation of the first Patient Family Advisory Board of 2021 was a success! The meeting saw the participation of four patients, during which many ideas and topics were discussed. We encourage patients, family members, or others interested in CF to join us for our next meeting on April 22nd at 12 PM EST Your input and suggestions are greatly appreciated!

Join Zoom Meeting: <https://ufl.zoom.us/j/98817878488?pwd=Zk1QMTVzQllkUzdXQkdTWXZkR2k4UT09> / Meeting ID: 988 1787 8488



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