

CF Connection

Spring 2021

University of Florida Pediatric Pulmonary 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! Send them to hillajb@peds.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.



Financial & Nutrition Resources

Due to the pandemic, many families have experienced changes in income and unforeseen expenses. To offset some of these cost-of-living expenses and medical costs, some nonprofit organizations have funded grants for people with CF and their families. If interested in exploring financial grants and other support services, please contact our CF Social Worker Tatianna Pulcini (352-627-9325) and/or the CF Compass Program (844-266-7277).

USDA extends child nutrition programs: The United States Department of Agriculture (USDA) has extended waivers for child nutrition programs through September 30, 2021. This will allow continued access to free meals for all children over the summer, regardless of income. To find a location near you, visit <https://www.fns.usda.gov/meals4kids>. Compass case managers can also help locate food resources; visit <https://www.cff.org/Assistance-Services/About-Compass/What-Is-Compass/>.

Upcoming Events & Opportunities

Upcoming Virtual Events

Mental Health & Cystic Fibrosis – Tuesday April 20th 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

ResearchCon – April 15th and 17th

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 30th. For more info, please visit <https://www.abbviecf scholarship.com/>.



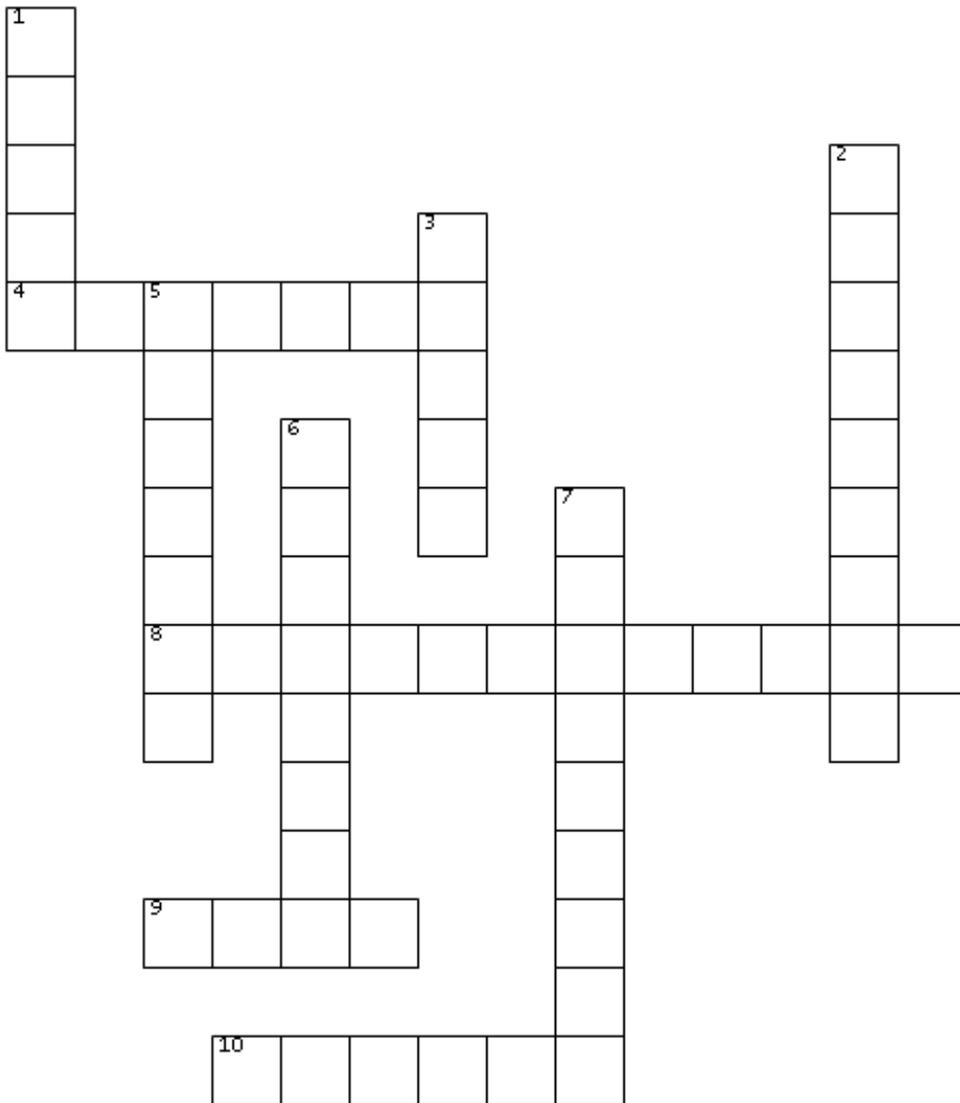
Research Opportunity

Is your child using a CFTR modulator like Kalydeco, Orkambi, Symdeko, or Trikafta? If so, there is a study opportunity 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 child's 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: Your child can participate more than once if he/she ever switches to another modulator.

Cancelling or Rescheduling Reminder

Once you have been scheduled for clinic, please make every effort to arrive on time. If you realize you are unable to attend your appointment, please contact us immediately (352-273-8380) to reschedule. Keep in mind, we schedule patients based on microorganisms grown, so this may mean that you will have to wait several weeks to be rescheduled. We are only able to schedule a certain amount of patients each day, so if you have an appointment and don't show up, you are taking away an appointment time that another patient could use.

Learn About CF!



ACROSS

4. Having no germs
8. Worsening of CF symptoms which require extra medicine or a hospital stay
9. An Airway Clearance Method that vibrates quickly to loosen mucus in the lungs
10. Makes it easier to use an inhaler. It attaches the inhaler to a mouthpiece or mask. When the medication from the inhaler is released, it's held here until the person is ready to breathe it in

DOWN

1. Sticky stuff inside your nose, mouth, lungs, stomach, and intestines that protects and lubricates your body
2. Therapies designed to address the basic cause of CF—a defective protein called CFTR
3. Organisms that can cause infection. This includes bacteria, fungi, and viruses
5. Substance needed for the proper digestion and absorption of food
6. Nutrients that help our bodies grow, function normally, and fight illness
7. A machine that turns liquid medicine into a mist that can be breathed in

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