

CF Connection

Spring 2022

University of Florida Adult Cystic Fibrosis Center

April is Move More Month

Your CF care team wants to encourage everyone to be active this month and every month!

Why is it important?

Physical activity can help you be stronger and healthier – both mentally and physically. Benefits of physical activity range from better mood to weight management to stronger bones and muscles. Did you know that regular physical activity can also help you sleep better and help improve lung function? Kids who get regular physical activity are more likely to do better in school! For more reasons to be physically active, visit [Benefits of Physical Activity | Physical Activity | CDC](#).

How much is enough?

Experts recommend kids ages 6-17 get at least 60 minutes of physical activity every day. Toddlers and young children are encouraged to be active with their family every day, but they don't have a specific goal. Adults should aim for at least 150 minutes per week of moderate-intensity activity. Remember that any amount of activity is better than none and it doesn't have to be done all at once. If you and your family aren't very active now, start slowly and gradually work up to more active time.

Which activities are best?

Any activity that you enjoy and that moves major muscle groups is a good type of activity. The easiest way to be active is to put on your sneakers and go for a walk. Start slowly and gradually increase your speed (intensity) and distance. If you have physical limitations, talk to your doctor

about a safe plan. People with CF can get a plan for safe and effective activities with a Physical Therapy evaluation – ask about this at your next CF clinic visit!

Make physical activity fun for kids and help them find activities they enjoy, such as biking, skating, jumping rope, playing basketball, or dancing to a YouTube video. Encourage your kids to participate in school sports or join a community pool or recreation center if possible. Be a role model for your kids – if you are active, they will be more likely to be active too!

Limit screen time

Watching TV, playing video games, and using digital devices takes away from time that can be spent being physically active. Too much screen time is bad for physical and mental health and can interfere with sleep. It can also lead to delays in brain development (such as speech and language delays in young children). Experts recommend:

- * children under age 2 should avoid all screen time.
- * children ages 2-5 should have no more than one hour of high-quality, educational screen time daily.
- * ages 6 and up should ensure screen time does not interfere with sleep or exercise.

There is not a screen time recommendation for adults but most adults could benefit from spending less time with their smartphones, TVs, computers, and other digital devices.

Just Do It! What are you waiting for? Put down your phone and be active!

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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.

Setting Exercise Goals

When trying to change any habit, it's important to set realistic, achievable goals that are relevant or important to you. Perhaps you have had the experience of beginning to exercise or even buying a gym membership January 1st as part of a New Year's resolution only to stop a few weeks later because we set unrealistic expectations (such as going to the gym 6 days per week every week). Setting "SMART" goals can help prevent burnout when forming a new habit, such as increasing physical activity. When you meet your goal, it's also important to reward your hard work and acknowledge your effort. We encourage you and your family to give SMART goal-setting a try!



Setting goals can be a great way to challenge yourself to make healthy lifestyle changes. Set yourself up for success by making your goals SMART!

SPECIFIC	MEASURABLE	ATTAINABLE	RELEVANT	TIMELY
What is your goal?	How will you keep track of your progress?	How will you achieve your goal? Make a plan!	How will this goal help you?	When will you achieve this goal?

Example SMART goal:

S: I will increase my weekly physical activity by swimming for 1+ hrs 3x per week in the pool.

M: I will track my swimming by writing an "X" on my wall calendar on days that I swim.

A: I will start working on this goal on Monday after my band practices end for this quarter.

R: Swimming 3x per week will help me increase my regular physical activity, improve my health (cardiovascular health, stamina, strength!), and improve my mood.

T: I will review my progress monthly and adjust my goal as needed to maintain regular physical activity (e.g., increase number of days of swimming if I easily meeting my goal, change the activity if barriers to swimming arise).

Reward: For each week that I achieve my goal, I will play a card or board game with my family, go to the library to pick out a new book, watch a new movie, or go to a museum that weekend.

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! See all that Beam has to offer at <https://beamfeelgood.com/on-demand/cystic-fibrosis>

Pharmacy Update

If your prescriptions were transferred from Kroger Specialty Pharmacy to Walgreens, you unfortunately may be having some delays. All prescriptions were transferred, but the new pharmacy must validate the prescription directly with our office and may need to have new prior authorizations completed (more paperwork and more delays). Additionally, Walgreens may not be in-network with your insurance and some people may need to find an in-network specialty pharmacy. [CF Foundation Compass](#) can help you if you have any issues with insurance or network coverage.



Research News

Research is a great part of the Cystic Fibrosis Foundation since studies help with discovering new and effective CF therapies. The CF Foundation supports a wide range of innovative research to tackle the disease from all angles. At UF, we enrolling patients for two research studies. One of those studies is called SIMPLIFY (for ages 12 and up), whose purpose is to test whether it is safe to stop taking inhaled hypertonic saline or domase alfa in those people that are also taking TRIKAFTA. Another currently active study is called PREDICT (for ages 6 and up), which is to investigate if people with cystic fibrosis who have grown nontuberculous mycobacteria (NTM) germs from sputum would benefit from treatment since NTM is an unusual bacterium that can be difficult to treat. New research studies may be coming our way to find effective ways to fight CF. To see if you or your child qualifies for a research study, ask at your next clinic visit or email Darlin at darlin.ramirez@peds.ufl.edu.

How to Take TRIKAFTA®

Taking Trikafta® with fat-containing foods helps the body absorb and use this medication. There is no exact recommendation about how much fat is needed, but a goal of 10-15 grams of fat should be enough for teens and adults. For younger children, aim for a minimum of 5 grams of fat.

What kind of fat is best? We used to be more concerned about people with CF getting enough calories (and eating high-fat foods is a good way to do that) and not as concerned about the type of fat people with CF ate. However, It's important to choose foods with "healthier" fats more often. Polyunsaturated and monounsaturated fats (rather than saturated fats) have important health benefits, including heart health.



Try These "Healthier" Fats

- 1 hard-cooked egg (5g fat)
- 10 large black olives, pitted (5-6g fat)
- 2 tbsp. trail mix (5g fat)
- 4 tbsp. hummus (5g fat)
(serve with pita bread or veggies)
- 3 tbsp. guacamole (7g fat)
(serve with bagel chips)
- 1/4 of an avocado (7g fat)
(spread on toast or add to smoothie)
- 1 tbsp. peanut butter (8g fat)

CF Connection—Adult Cystic Fibrosis Center

Please Welcome Latrice!

We are excited to introduce Latrice Williams, our new licensed clinical social worker! She is a wife and mother of 2 children ages 12 & 9. She graduated from Saint Leo University with a Bachelors in Social Work in May of 2017. She earned a Master's degree in Social Work with a concentration in child and family from Walden University in November 2019. Latrice is the Founder & President of a non-profit named Holding Hands & Healing Hearts Inc., which is a 501c3 mentoring organization to motivate and empower females age 8+. Latrice has a passion for others and to serve in their time of need. She values herself on helping those that may be unable to help themselves. She serves as an advocate and leader for her community. Latrice has over 7 years in the healthcare field where she has served in many different positions all in the aspect for serving others & has earned 16 customer service keys. Latrice has provided counseling services in her local high school and in the community as a mental health therapist.



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Miscellaneous News & Events

Great Strides: Get your steps in AND help raise money to help fight CF by joining one of the CF Great Strides walks! Most walks in Florida will be held in April and May. To find a walk near you, visit <https://fightcf.cff.org>



The Cystic Fibrosis Foundation has a YouTube channel!

Visit [Cystic Fibrosis Foundation - YouTube](#) for TONS of videos about research, new medications, past CF conferences, and more!

UF Patient Family Advisory Council aims to ensure positive patient outcomes and satisfaction by improving the quality of care at our clinic through patient feedback and initiatives. It's open to all patients at our CF clinic.

2022 ZOOM meetings at noon on 06/16, 07/14, 08/18, 09/15, 10/20, 11/17, 12/15
Zoom ID: 967 592 5101

UF CF Center Virtual Patient Education Day will be May 19th @ 5:30pm—

this is an opportunity to interact with a diverse CF community to discuss important topics related to CF Care. Patients, caregivers, families, and medical professionals interested in CF are welcome to attend. ZOOM ID: 967 592 5101