

CF Connection

Spring 2020

University of Florida Pediatric Pulmonary Center

COVID-19
Special Edition

We Are Here for You!

During this challenging time, we want you to know that the entire CF team continues working to provide quality care for our CF patients and families. Here is what we are doing:

- We are continuously monitoring the COVID-19 situation and following the recommendations of the Centers for Disease Control and Prevention (CDC), Cystic Fibrosis Foundation (CFF), state and local health departments, and UF Health. Please click on these links for the most updated information:
CDC: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>
CFF: <https://www.cff.org/>
State of Florida: <https://floridahealthcovid19.gov/>
Alachua County: <http://alachua.floridahealth.gov/>
UF Health: <https://coronavirus.ufhealth.org/>
- Many of us are working from home and we are having all of our team meetings via Zoom. The staff who are in the office, hospital, and clinics are practicing social distancing and we continue to wear personal protective equipment when we are with patients in the hospital or clinic.

- We are trying to have all regular clinic visits via telemedicine using Zoom. Our office will contact you before your scheduled clinic visit with instructions. All you will need is a smart phone, tablet, or home computer with internet access. If using your smart phone or tablet, please download the Zoom app before your appointment time (you don't need the app if using your computer). Please see page 7 for tips on how to make the most of your telemedicine visit.
- We will continue to admit patients to the hospital as needed but we may be able to treat your child at home. If your child is sick with increased cough, fever, shortness of breath, or any other issues, please call our office at **352-273-8380**. We will either schedule a telemedicine visit for the same day you call (if possible) or give you instructions for bringing your child to the hospital. If you think your child has been exposed to COVID-19 but does not have any symptoms, please still give us a call and we can schedule a telemedicine visit.

We will all get through this together! Please contact us if you have any questions.

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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 us at the address on page 7 or e-mail them to hillajb@peds.ufl.edu.

Tips for You and Your Family at Home

- ✓ Stick to a routine. Go to sleep and wake up at a reasonable time, write a schedule that includes time for work as well as self-care.
- ✓ Dress comfortably. Get showered and dressed in comfortable clothes, wash your face, brush your teeth. Put on some bright colors. It is amazing how our dress can impact our mood.
- ✓ Get out at least once a day and try to exercise for at least 30 minutes. Go first thing in the morning, or later in the evening, and try less traveled streets and avenues. Search for free movement classes on YouTube or turn on the music and have a dance party!
- ✓ Reach out to others. Try to do FaceTime, Skype, phone calls, texting, wave to your neighbors. Do it for your children as well—they miss their friends, too!
- ✓ Drink plenty of water and eat as well as you can.
- ✓ Develop a self-care toolkit. Keep your favorite things around you: a soft blanket or soft toy, favorite photos, comfort food, favorite music, coloring books and paints, books. Mint gum, Listerine strips, ginger ale, frozen Starburst, and ice packs may help control anxiety. For children, help them create a comfort box (often a shoe-box or bin they can decorate) filled with their favorite things and that they can go to when they feel overwhelmed.
- ✓ Give everyone the benefit of the doubt, forgive generously. Everyone is doing the best they can.
- ✓ Everyone find their own quiet space. It is good to know that even when we are on top of each other, we have our own special place to go to be alone.
- ✓ Limit social media and COVID conversation, especially around children. There is so much information on COVID-19, and it changes minute to minute. Find a few trusted sources and check them a few times a day.
- ✓ Notice the good in the world and help others. Very small acts of kindness make us feel good about ourselves and make all the difference.

NEW WEEKLY ONLINE DISCUSSION/ SUPPORT GROUP

TO COPE WITH COVID-19 STRESS

Thursdays at 5:00 pm PT / 8:00 pm ET

Moderated by psychiatrist Yelizaveta Sher, MD, Adult CF Center at Stanford

CFRI will host an online discussion/support group for members of the CF community. This is an open format via Zoom where people can share their experiences and address the anxiety that COVID-19 is triggering in our community.

To participate, go to <https://zoom.us/j/519241333>

Wellness During COVID-19

The UF Pediatric CF Team is here and available to help support you and your family during this time. When you have a moment, we encourage you to review the following resources. We hope that they will be helpful!

Self-Care Strategies:

- Stress Management: [CF Exchange Stress Management Tip Sheet](#)
- Comprehensive Caregiver Guide: [NCTSN Caregiver Guide to Helping Families Cope with Coronavirus](#)

Discussing COVID-19 with Your Children: Coronavirus can be a confusing topic for your children and teenagers. Below are some resources that were specifically developed with kids and families in mind:

- General Parent Strategies: [Cincinnati Children's Steps to Help Ease Kids Fears & Anxieties](#)
- Children: [NPR's Comic Exploring the New Coronavirus](#)
- Teens: [Child Mind Institute's Supporting Teenagers and Young Adults during the Coronavirus Crisis](#)

FL Blue Emotional Support Helpline: Free counseling support available 24/7 in English & Spanish - 833-848-1762

Please do not hesitate to reach out to Dr. Fedele at 352-294-5765 with any questions or concerns.

Resources for Uncertain Times

General Assistance - Need Help? Call 2-1-1

2-1-1 is a free resource referral service provided by United Way that connects area residents to critical health and social services when they need help. From help with a household bill, food assistance, or counseling for suicide prevention, calling United Way's 2-1-1 helpline is open 24 hours a day, 7 days a week, year-round.

Connect in the following ways:

- Dial 2-1-1 (24 hours a day, 7 days a week)
- Text your zip code to 898-211
- Search their [resource database](#) online.



Employment Resources

Florida Department of Economic Opportunity has initiated two programs to address the work-related impact of COVID-19. For full details visit their website [here](#).

- **Re-Employment Assistance** is temporary wage replacement program caused by COVID-19. FAQs can be found [here](#).
- **Business Recovery** - Offering small businesses emergency interest-free bridge loans. More info can be found [here](#).

Educational Resource Database - Updated daily and completely free. They also maintain a Facebook group with great ideas of how to educate and entertain your children during while the schools are closed. More info can be found [here](#).

Have a specific issue that hasn't been addressed?

Contact the CF Social Worker, Tatianna Pulcini, to see if additional supports are available at 352-627-9325.

Nutrition Resources

Healthwell Foundation COVID-19 Ancillary Costs Grant can provide up to \$250 to cover costs associated with delivered food, medication, diagnostics, transportation, and telehealth. Family income must fall within 500% of Federal Poverty Level. To see if your family qualifies, click <https://www.needymeds.org/poverty-guidelines-percents/>. For more info about applying, visit <https://www.healthwellfoundation.org/fund/covid-19-fund/> or call 800-675-8416.

Drive Thru Farmers Market is available at Working Food, 219 NW 10th Avenue, Gainesville. Participating farms have produce, dairy products, meats, bread, and more. Market days are Wednesday (4-6pm) and Saturday (9-11am) through April 11. Orders must be placed with participating farms two days in advance. Find Working Farm on Facebook or visit www.workingfood.org for the list of farms, links to online ordering, and updates on the market. For more information, contact Working Food at www.workingfood.org or 352-260-4458.

Summer BreakSpot offers free meals for children under age 18 in the state of Florida. Many schools are offering take-home lunch bags. To find a local site, click <https://summerbreakspot.freshfromflorida.com/> or contact your child's school.

Academy of Nutrition and Dietetics offers information about food safety, tips for grocery/meal delivery, tips for grocery shopping, food resources, and more! Click [here](#).



Eating Healthy During COVID-19

A lot is changing in the world right now with the new public health crisis. Despite the uncertain times ahead, one thing remains constant...we need to eat! When you have a child with cystic fibrosis, it can be even more important to plan nutritious, high-calorie meals with shelf-stable foods (foods that will stay safe to eat for a longer period of time and do not need to be refrigerated).

Here are some high-calorie shelf-stable foods that may or may not need to be refrigerated upon opening. Keeping these items on hand can help ensure your child gets enough calories through these trying times.



Food Item	Calories	How to Use
Nuts (cashews, almonds, walnuts, etc.)	180 calories per ¼ cup	Excellent as a snack or add to cereal
Nut Butters (peanut butter, almond butter, etc.)	190 calories per 2 tbsp	Add to fruit or mix into oatmeal
Oils (olive, peanut, vegetable, corn)	110 calories per 2 tbsp	Add to pasta, drizzle on vegetables
Creamy Soups (clam chowder, cream of mushroom)	185 calories per 2 tbsp	Eat with buttered crackers
Alfredo Pasta Sauce	90 calories per ¼ cup	Add to your favorite pasta
Cheesy Queso (Tostitos, Velveeta, etc.)	85 calories per ¼ cup	Pour over broccoli
Canned Gravy	120 calories per cup	Pair with dehydrated mashed potatoes
Mayonnaise	180 calories per 2 tbsp	Make tuna or egg salad
Ranch Dressing	100 calories per 2 tbsp	Use as a vegetable or pizza dip
Maple Syrup	100 calories per 2 tbsp	Add to oatmeal or pancakes/waffles
Dried Whole Milk	150 calories per 1 cup	Drink plain, add powder to pasta sauce
Boxed Whole Milk	150 calories per cup	Drink plain or add chocolate syrup

Kid-Friendly Recipes

Tacos! Kids love anything they can touch or hold - this includes finger foods! Tacos are a great food as they allow kids to touch and hold the food. This gives them a sense of power and allows them to explore their curiosity! In addition, tacos are great because allowing your child to add toppings gives them some control over the foods they like, which makes them more willing to try it and eat it.



Ingredients

- 1 lb. ground turkey
- 1 packet taco seasoning
- 1 (15 oz) can kidney beans or refried beans
- Multigrain tortillas
- Shredded lettuce
- 1 T shredded cheddar cheese
- 1 T sliced avocado
- Diced tomatoes
- 3 T Olive Oil

Instructions

1. Brown taco meat with olive oil
2. Add taco seasoning mix based on instructions
3. Add kidney beans to mix
4. Take a multigrain tortilla, and add 2 oz meat mix
5. Top with 1 T shredded cheese, 1 T diced avocado, shredded lettuce, and diced tomatoes. Enjoy!

1 taco = 350 calories, 15 g fat, 13 g protein

Butternut Squash Noodles with Broccoli—Offer your child vegetables every day. Even if they don't eat the vegetables, offering them is a great way to get your child familiar with veggies. And the more familiar they are, the more kids are likely to eat them! Adding butternut squash to the alfredo sauce in this recipe is a great way to add extra nutrients without your little one noticing! Adding olive oil into the alfredo sauce is a great way to add extra calories if your child needs them.

Ingredients

- 1 cup frozen cubed butternut squash
- 3 cups frozen broccoli florets
- 2½ cups full-fat alfredo sauce
- 3 tbsp olive oil (optional)
- 16 oz box wagon wheel pasta (or pasta of choice)

Instructions

1. Boil and drain wagon wheel pasta, then set aside for later.
2. Microwave butternut squash and broccoli as recommended on package.

3. In a blender, blend butternut squash until smooth. Add small amounts of water if needed.
4. In a large saucepan, simmer alfredo sauce and whisk olive oil into the alfredo sauce. Next stir the blended butternut squash into the sauce.
5. Add the cooked wagon wheel pasta to the saucepan and stir well to coat the pasta.
6. Add the broccoli and serve!

1 cup (with added oil) = 360 calories, 14 g fat, 9 g protein



Family Corner

Family Advisory Council

The UF CF Center wants your help to make life better for our patients with CF. Consider joining our Family Advisory Council! For more details, contact any member of your child's CF team.



All regular clinic visits will now be telemedicine visits so you and your child do not need to be seen in person. Make the most of your TELEMEDICINE visit with these handy tips:

Before the telemedicine visit

- Our office will call you to confirm your appointment time and then send you instructions for connecting to Zoom through your smartphone, tablet, or home computer.
- Download the Zoom app to your phone or tablet. If you are using a home computer, you do not need the app. Be sure the speakers and camera are working.
- Have your child with you at the appointment time. Try to be home in an area with good phone/internet connection. Do not be in a moving car since this may cause a bad connection and also is not **be** safe!
- If you have them at home, have these items nearby: thermometer, scale, pulse oximeter, and/or a portable PFT machine.
- Connect to the call a few minutes early.
- Think about what you want from the visit and what questions you have.

During the visit

Ask questions. Here are some tips to get you started:

- "Can you repeat that?"
- "Let me repeat what you just said so that I know I understand."
- "I need to write that down."
- "Will the clinic follow up with me or should I contact the clinic directly?"

For more helpful information, check out the UF Pediatric Pulmonary Center Patient and Family-Centered Toolbox: <https://pulmonary.pediatrics.med.ufl.edu/>

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