



Adult Cystic Fibrosis Center Quarterly Newsletter

North Central Florida Cystic Fibrosis Conference

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We had our first North Central Florida Cystic Fibrosis Conference on Friday March 9th, 2018. Dr. Lascano, Dr. Leey, and Dr. Morelli spoke about CF and its care and management. Guest speaker Dr. Marcia Katz, from the University of Central Florida, spoke to the crowd about the importance of transition from pediatric to adult CF care and Nikolas Job gave a patient's experience living with CF. In all, we had about 150 people from north and central Florida. It was great to see your family members attend and interact with our team outside of clinic. Our conference was recorded for you to get in on the action! Please click on the link to watch our inaugural CF Conference!

<https://mediasite.video.ufl.edu/Mediasite/Catalog/catalogs/-north-central-florida-cystic-fibrosis-conference-2018>

Annual Labs Reminder

Remember that your CF labs are to be done every year. These labs help us make correct decisions about your health and care plans.

Labcorp and Quest lab draws can now be done in the Medical Plaza lab.

If you have any questions, please ask us!

New Vertex Drug Available

Symdeko is the tezacaftor/ivacaftor medication used for the treatment of CF. You must have two copies of the F508del mutation, or have at least one mutation in the CF gene that is responsive. During your next scheduled appointment, the team will discuss your eligibility.

Why Participate in Cystic Fibrosis Research?

Why do people need help in CF research? The reasons are easy but important.

1. It is only through research that we can get a better understanding of the disease. We have learned more about the causes of CF, how it works and how it affects people through research.
2. Research helps us learn better ways to treat the condition. Only a few medications and treatments specifically targeting cystic fibrosis are available to patients. These drugs can only help in handling the symptoms. Maybe more ways of dealing with the disease will come later through research.
3. In the future, research may be able to find a cure. Right now, cystic fibrosis is considered treatable, but not curable. Continuous and widespread research can change this.

CF Roundtable

CF Roundtable is a newsletter for Adults with CF created by the CF Foundation. Articles are written by people from all over the country about relevant information and changes in the CF community. CF Roundtable is free to everyone and can be read at this link <http://www.cfoundtable.com/newsletter/download-your-newsletter/>

Annual Patient Engagement Survey

We will be handing out our patient survey from April to June 2018. Like last year, your responses and input will help us understand what is working in our clinic and what changes we need to make. Some helpful suggestions from last year included less handouts in clinic and improvements in communication through epic. We are looking forward to hearing your suggestions this year!



Patient's Corner Featuring Jo Weaver



I often find myself in disbelief at my new chapter as a doctoral student. I've always enjoyed school, learning, and a challenge, but I never foresaw my chance to pursue these proclivities to this degree (how punny). I credit my good fortunes to the wonderful health care I have received throughout my life, the support from family and friends, and my unyielding positivity.

My parents instilled positive thinking in me as a child. Despite my CF, they refused to settle for my life being unfulfilled. We found the beauty in the everyday, which, lucky for us, was easy to do living in the middle of an 80-acre farm. Now, I find myself utilizing these positive thinking/mindful strategies with my chosen profession of counseling.

Just as I tell my clients, I try to find a blessing in each day, and practice gratitude even though some days can be difficult. When your sinuses are flaring, your cough is back, or you forgot to take your enzymes, positivity and gratitude may seem inapposite; yet, if I can find something, no matter how small, to be thankful for my pain seems to lessen and my prospective broadens.

CF Recipes

Avocado Pasta (670.7 calories per serving)

Ingredients:

12 oz. spaghetti
2 ripe avocados, halved, seeded and peeled
1/2 c. fresh basil leaves
2 cloves garlic
2 Tbsp. freshly squeezed lemon juice
Kosher salt and freshly ground black pepper, to taste
1/2 c. olive oil
1 c. cherry tomatoes, halved
1/2 . canned corn kernels, drained and rinsed

Instructions:

1. Cook pasta in a large pot of boiling salt water according to package instructions. Drain well.
2. To make the avocado sauce, combine avocados, basil, garlic and lemon juice in a food processor. Season with salt and pepper to taste.
3. With the food processor running, add the olive oil in a slow stream until emulsified. Set aside.
4. In a large bowl, combine pasta, avocado sauce, cherry tomatoes and corn.
5. Serve immediately. Serves four people.



Upcoming Events

Gainesville 2018 Great Strides

Date: 4/14/2018
Check-in: 8:00 AM
Walk: 9:00 AM
Distance: 5k
Event Location: Westside Park,
Gainesville, FL



The UF Adult CF Team will be in attendance. We hope to see you all there!

CF MiniCon: Sexual and Reproductive Health

April 8, 2018. This virtual event for adults with CF will provide an opportunity to discuss the impact of CF on sexual health, the decision to have kids, the parenting journey, and beyond.

Registration is here: <https://www.cff.org/Get-Involved/Participate/Participate-in-an-Event/Virtual-Events/CF-MiniCon-Sexual-and-Reproductive-Health/>

