

WINTER 2019

# CLINIC NEWSLETTER

*The seasonal newsletter for VCU Medical Center's Adult CF Program*

## DIRECTOR'S VISION

Dear Patients and Families,

I want to assure you that everything we do here at our CF center is for you: patients and families. CFF recently released 2018 registry data, and I want to share the improvements and the work we will be doing over the next year. I am very happy to share this with you, and I am sure you will be equally happy to see this.

1. Our BMI, which reflects nutritional outcomes, remained above national average.
2. Our PFTs, which reflect lung function, improved and now are above national average. This is excellent news!
3. Our clinic follow-ups to comply with CFF guidelines went up from 60% to 62.4%, which is above national average.

Our clinic's goals for 2020 are to offer you the most up-to-date CF care based on the latest research and our experience. We want to involve you in your care, also known as "shared decision making," and ensure access to our clinic by various means (e.g. clinic visits, phone calls, MyVCUHealth Portal).

We will keep participating in CF Foundation sponsored Quality Improvement (QI) projects. We use this to improve our quality of care. We are going to add a pharmacist and possibly a pharmacy tech to our team to expedite prior authorizations and assist patients. We are in process to add a GI doctor who can provide expert advice for CF belly-related issues. We are also partnering with palliative care to promote advance care planning conversations.

We will continue to improve participation in patient and family experience-of-care surveys, improve pre- and post-transplant flow, and guide our center to meet national goals set forth by experts at the CF Foundation. All our providers and team members meet monthly to review our quality improvement projects and research studies.

In October, we presented 3 abstracts at the national meeting in Nashville. We learnt a lot about the new pill Trikafta, which I am sure you know can help patients with 1 or 2 copies of 508 del. These patients can possibly gain 14% of lung function if they have 1 copies of the gene, and 10% if they have 2 copies.

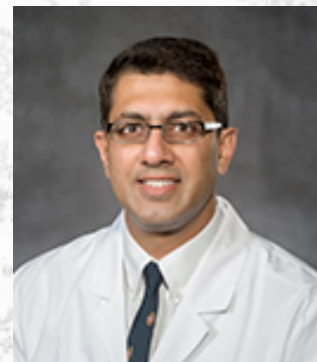
We explored new research trials which included all aspects of CF care, like new anti-infection and anti-inflammatory medications and ways to try cutting down CF treatments based on future trials. We saw quality improvement initiatives, CF exercise programs, and new airway clearance equipment. It was a wonderful way to network with our colleagues, and we are now ready to bring back our experiences and provide you with excellent care in a refreshed format!

Finally, several sessions reviewed CF's path to cure and gene editing, which I am very excited about in the future.

**As a reminder,** we have an email ListServ. It is a closed group that our patients and families can join with permission. If you are interested, please reach out to our social worker, Ansley.

Thank you very much for all your support to our center. It is my privilege to serve you and I wish you all the very best,

*Nauman Chaudary MD, FACP, FCCP  
Director, Adult Cystic Fibrosis Center*



# DR. C'S TIPS FOR A SMOOTH CLINIC VISIT

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Have your best clinic visit yet with  
Dr. Chaudary's top 5 tips!

All CF clinics run in their own style, and your previous CF clinic experience may be different from your experience at our clinic.

Please be aware that your *first* appointment will take **roughly 2 hours**.

Follow-up appointments are **about 90 minutes**.

In the VCU adult CF clinic, you will meet our multi-disciplinary team. We have a consistent workflow after you check into clinic. A staff member will check your vital signs (temperature, blood pressure, oxygen saturation, weight), and our dedicated registered respiratory therapist (RRT) will do your pulmonary function testing (PFT). After this, you will see your physician and may see our multidisciplinary team members (dietician, social worker, mental health worker). You will meet with the MD at each visit, and see the other team members at least annually, or more if you need to. After your visit is completed, you will be scheduled for your next clinic visit. If you need lab work, the lab is located right across from the waiting room. If you need x-rays, there is a radiology department on site. Please know that every week, we meet as a group to review all clinic patients, so everyone on the team is up-to-date and treatment plans can be adjusted if needed. Some visits may not require you to see the full team, depending on your overall health.

1. **Please arrive earlier than your given appointment time.** Check-in and PFTs can take 30-45 minutes. Coming in early will allow us to get you home sooner and prevent delays for other patients.
2. **Ask questions.** We do our best to educate and treat you, but our first priority is making sure that we serve your needs.
3. **Honesty is the best policy.** We are not here to judge you. We want to offer treatments that will not only give you the best chance to stay healthy, but also fit best with your lifestyle. We do like to be aggressive in treating your disease, but **you have the final say in your treatments**. Help us help you.
4. **Make your follow-up appointment before leaving clinic.** It is critical that we see patients quarterly- at least 4 times per year, about every 3 months, to catch any issues early and respond quickly.
5. **Keep us updated on your progress when you are home.** We have adopted the MyVCUHealth portal for non-urgent communications. This is also an excellent way for all team members to see how you are doing all in one, easy way.



# NEW STAFF SPOTLIGHT

## MEET ANSLEY CLARKE, MSW!



Ansley

Meet Ansley Clarke, MSW! Ansley is the new adult CF team social worker! She completed her graduate degree in social work here at VCU, and started her time working in the emergency department. Ansley has experience working in both the mental health and medical fields, and is so excited to be a part of the VCU Health CF family! She will be in Dr. Burns' clinic on Tuesday mornings, and Dr. Chaudary's clinic on Wednesdays. On those days, you can find her meeting with patients to do assessments and talk about a variety of issues, including their treatment plan, affording their medication, coping strategies and self-care, and their day-to-day lives! The rest of the week, Ansley is usually downtown at the hospital, visiting inpatient CFers and working on projects for our program.

In her spare time, you might see Ansley enjoying some hot yoga or hiking with her husband and her miniature dachshund, Zoë Marie! You can reach Ansley at (804) 828-8676, by portal message, or at [ansley.clarke@vcuhealth.org](mailto:ansley.clarke@vcuhealth.org).



Zoë Marie

# IT'S THE SEASON TO BE COUGHING

**NARISA TURNER, RRT**

## **Get the Flu jab.**

The flu can be detrimental to the health of someone with CF. Don't risk it. Get your flu immunization from your general practitioner, your CF physician, or even your local pharmacy.

## **Get on it.**

Attack your colds right away. Drink more water and get more rest/sleep. At the first sign that the cold is not going away and you are getting worse, let the doctor know. If you get to the point where you cannot get better on your own, be ready to accept the idea of being admitted into the hospital to get that help you need.

## **Get to the rescue.**

If you have worsening symptoms (like wheezing or excessive coughing) after maybe catching a new virus, do your quick-relief medications (e.g. rescue inhaler such as Albuterol MDI). It's amazing how an extra treatment or two can make you feel. Notify your doctor if symptoms are not relieved or get worse after extra treatments.



*In addition to the beauty that the cold season brings, the cold weather can have some undesirable effects on the health of CF patients. This is why we wanted to share some good habits and tips that our CF community can use during the cold weather season.*



## **Get aqua.**

Stay hydrated by drinking fluids all the time. It's easy to get dehydrated in the winter. Consider drinking warm, decaffeinated herbal teas, especially if you are on the go (in a thermal mug).

## **Get warm.**

A good coat and a warm pair of boots are key in not ending up sick. Loosely wrap a scarf around your nose and mouth to warm the air before it enters your lungs. Always try to breathe in through your nose and out of your mouth. Let your nose warm and moisten the cold air you breathe in.

## **Get out (weather permitting).**

Don't be a "shut in." Get out of the house, even if it's just to run errands or take a walk or a drive. Especially on a sunny day, get some fresh air and some vitamin D. As always, in public places like the airport, restaurants, grocery store, or the gym, always wash your hands or use hand sanitizers to eliminate germs.

## **Get moving.**

Find a way to stay active like walking the dog or exercising every day. At home, you can YouTube with exercise apps. Don't have money for gym membership? Try to apply for one of the CF Foundation Grants provided by the CF Foundation such as the Cystic Fibrosis Lifestyle Foundation (CFLF), the Empower Project, and the Miles for Cystic Fibrosis. All of these grants are for CFers to take part in activities that will improve their mental and physical health.



# SELF-CARE CORNER:

## HOLIDAY SELF-CARE

ANSLEY CLARKE, MSW



*The holidays can be a tough time for anyone, but they can be especially tricky when you are trying to keep up with treatments and enjoy time with loved ones. Here are some tips to stay on track this Winter.*

Get active! The holidays can bring joy, but they can also bring stress!

Do your best to move your body every day. Try a yoga video, go for a walk, or do some stretches. Exercise activates dopamine and serotonin to reduce stress and keep you feeling great.

Get enough sleep. This can be tough, whether symptoms, stress, or holiday schedules are keeping you up. Set aside time to GET to sleep and BE asleep. Put electronics away and try reading, writing, or some music for at least a half hour before bed.

Treat yourself! As you know, CF is no reason not to have fun. Make plans that keep you excited and motivated throughout the season. Your clinic team is always here if you need a boost!

Keep up with your treatments!

It's easy to get distracted by holiday plans and let CF care fall to the side. To feel your best this season, take time to keep symptoms at bay and fun at the forefront.

Keep a gratitude record- and get creative! I celebrate Christmas, so I make a gratitude tree. I have a green paper tree with 31 colorful paper ornaments. I decorate the tree at the beginning of the month and write something I am grateful for on one each day! You can also use a jar or other container, or a journal. When things feel tough, remembering what we are grateful for can keep us grounded.



# HOLIDAY CF RECIPE

## PEANUT BUTTER NO-BAKE COOKIES

<https://www.livewellbakeoften.com/peanut-butter-no-bake-cookies/>

*These no-bake cookies are delicious and so easy to make! They are guaranteed to be a popular holiday treat.*

### **You need:**

- 1/2 cup unsalted butter cut into pieces
- 1 and 3/4 cups granulated sugar
- 1/2 cup milk
- 3/4 cup creamy peanut butter
- 1 tsp pure vanilla extract
- 3 and 1/4 cups quick-cooking oats

- 1. Line a couple of large baking sheets with parchment paper.**
- 2. Place butter, sugar, and milk in a saucepan over medium heat. Stir until butter is melted and everything is well-combined. Bring mixture to a rolling boil and allow to boil for 60 seconds without stirring.**
- 3. Remove from heat and stir in peanut butter and vanilla until fully mixed. Stir in oats and mix until the oats are coated with mixture and everything is well-combined.**
- 4. Drop spoonfuls of mixture onto the prepared baking sheets. I like to flatten the cookies out a little.**
- 5. Allow to cool for 45 minutes to 1 hour or until cookies have firmed up.**

**Serve and enjoy! The cookies will continue to firm up more the longer they cool.**





# UNDER CONSTRUCTION...

## A NEW AND IMPROVED ADULT CF WEBSITE

Find resources on CF, insurance, resources and more on our new CF clinic website, coming soon! Let us know what you would like to see, and we will make it happen! Our goal is to have a one-stop shop for you to get what you need if our team is not immediately available. Feedback is always welcome!

## WE WANT YOUR INPUT!

- WHAT DO YOU WANT TO LEARN ABOUT?
- HAVE SOMETHING TO SHARE WITH OTHER PATIENTS OR CLINIC STAFF?
- WANT TO BE FEATURED IN OUR NEWSLETTER?

*REMEMBER! This is YOUR clinic! Please contact Ansley at 804-828-8676 or [ansley.clarke@vcuhealth.org](mailto:ansley.clarke@vcuhealth.org) to let your voice be heard!*