

Introducing Narisa Turner, RRT– the Adult CF Program’s New Respiratory Therapist!

I have been a Respiratory Therapist for 21 Years with my initial, formal training in NICU/PICU (neonatal ICU/pediatric ICU) here at VCU. I have worked at Children's Hospital of Richmond on Brook Road for 14 years. I have also worked at Henrico Doctors' Hospital, St. Mary's Hospital, CJW Medical Center, and Memorial Regional Medical Center.

I received my associates from J. Sargeant Reynolds and my B.S. in Business Administration from Old Dominion University.

I know first-hand what it is like not being able to breathe. From childhood, I have had asthma. I always hated taking my oral medications but I soon learned to be compliant in order to breathe. One of my greatest accomplishments is that I ran and completed my first 10K as an adult asthmatic.

I am a foodie. I love to cook, even bake on occasion, attend food festivals, and try new foods- especially desserts. I also enjoy watching movies from scary to romantic comedies. Something unique about me is that I love thunderstorms.

We are so excited to have Narisa join our team full-time! You can find her at your CF clinic appointments as well as inpatient.



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Message From the Director

By Nauman Chaudary, MD

Quality Improvement and Directors vision for 2019/2020

As CFF released 2018 registry data in the past few weeks, I am pleased to share the improvements and work we will be doing in our adult center over the next year.

- Our BMI which reflects nutritional outcomes for CF patients improved and now we are above national average overall. Our BMI for male patients remains below national average.
- Our PFT which reflects lung functions for CF patients improved but overall remain slightly below national average. We are above the median for adult CF programs in country which is great news.
- Our clinic follow ups to comply with CFF guidelines went up from 43% to 60% which is above national average as compared to last year.
- Our patient and family experience of survey data guides us that we are performing very well in many facets of adult CF care. We are considered a top program in country to provide adult CF care. There were few areas where we will work on enhancing communication between our CF team internally as well as try to increase participation by our CF patients who attend clinic and inpatient care at VCU.

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Goals for 2019/2020:

Our clinic's goals for 2019/2020 are to offer you the most up to date CF care based on the latest research and our experience. We want to learn as much about you and **your** CF so we may deliver the best care for you, as opposed to a "one size fits all" style. 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, My VCU Health). We will strive to keep ourselves and you updated on the latest advances in cystic fibrosis care and offer you the opportunity to participate in clinical trials which you may qualify for. We will also make efforts to continuously improve our center and to involve our patients in that process as we look forward to working with you!

Our center is participating in a CF Foundation sponsored Quality Improvement (QI) project called the Cystic Fibrosis Learning and Leadership Collaborative with several other CF centers. We at VCU participates in QI initiatives designed to improve our clinic flow, delivery of care, and patient care. This particular project involves Lung transplant referral for our Center. You may be asked to participate in this kind of research, which often includes questionnaires and interviews. We use this information to improve our quality of care.

Genoveva is participating in clinic coordinator mentorship guided by CFF expert. Dr. C is working on TDN clinical trials improvement work with TDN PIPE award of CFF and hiring a CF Pharmacist with support from CFF Pharmacy grant. Alexis is a Richmond's Finest Honoree of CFF and Liz serves on young professional Board of CFF VA Chapter. CF team is working with local Chapter for various fundraising activities and raising awareness of CF research. We have submitted approximately 3 abstracts to national meeting in October 2019 at Nashville. We will improve participation in patient and family experience of care survey, improve pre/post transplant flow and bring our PFT to above national average. All our providers and team members meet monthly to review various quality improvement projects that are ongoing in our center as well as research studies.

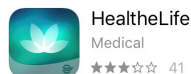
The big news in terms of new drug development was on the "TRIPLE" drug combination tezacaftor/ivacaftor and elxacaftor. Read on to learn more about this news in the research section of this newsletter.

As a reminder we have an adult email listserv. It is a closed group that only CF patients and families can join with permission. If you are interested in joining please review this with Alexis.

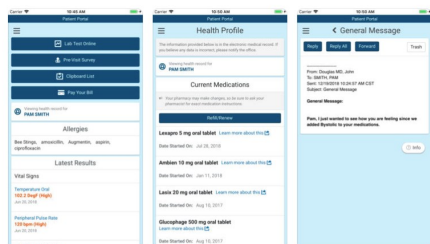
Thank you very much for all your support to our center. It is my privilege to serve you and I wish you all the very best,

Nauman Chaudary MD, FACP, FCCP

Director Adult CF Center



OPEN



Make sure you are subscribed to our official clinic listserv to receive communication from your CF team! Email alexis.bostetter@vcuhealth.org to add your email to our list.

Team Communication

Please utilize the patient portal when communicating with CF team members.

To send a portal message, log onto your account at <https://www.vcuhealth.org/my-vcu-health/my-vcu-health-online-records> OR log in via the "HealtheLife" smartphone app (see left).

You will notice only physicians' names will come up when you search in the "to" box. Select **"NAUMAN CHAUDARY, MD-CYSTIC FIBROSIS"** (see image on the right) and your message will go to a pool that is monitored by CF team members during business hours. Make sure to specify in the subject line or body of the message which team member you are addressing (i.e. social work, respiratory, dietitian).

Please avoid corresponding with CF clinic staff via email when discussing your clinical needs.

My VCU Health

< New Message

Do not use messaging for urgent matters! If you are experiencing chest pain, difficulty breathing, or suicidal feelings, please call 911!

Normal turn-around time is one business day.

If you do not receive a response to your message in a timely manner, please send a new message or call your clinic.

[View More](#)

* Indicates a required field.

* To
NAUMAN CHAUDARY, MD-CYSTIC FIBROSIS ✕

* Subject

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* Message

Getting Into Summer Time Fun!

By Jaclyn Sadicario, MS, Mental Health Coordinator

For many of us, summer time can be a time to relax and rest. Others may find a newfound source of energy— with longer days and warmer weather. Whatever it may be, summer can serve as an opportunity to connect with our most enjoyed activities. From what we know, both from personal experience and scientific literature, engaging in enjoyable activities can help support our mood and stave off a case of the blues. It could also impact how we see the world. However, with all of the things on our to-do lists, fitting in treatments, time with family, and making sure we get a good night's rest, it may be hard to find a way to fit in some time for joy. Joy does not have to take up a whole week, day, or hour! We can find joy in just a few minutes. Whatever it may be, starting anything new, set the bar a little lower and work your way up. Give yourself the space to feel good about small joys.

Here are some tools to help you make some time for fun this summer:

- Don't know where to start? Try picking something from the Pleasant Activities List. <http://uwaims.org/files/behavioral-activation/pleasantactivitieslist.pdf>
- Summer joy can be as simple as laying in the grass in the sun for five minutes or as grand as a day at the beach or the river.
- Make a plan in advance and figure out the details.
- Making sure to account for timing with treatments and transportation could make your summer venture stress-free. Also, it always helps to have something to look forward to.
- Ask a buddy to come along!
- We can always catch a movie or take a walk on our own time. However, research supports that having someone hold us accountable to our plans makes it more likely we will follow through.
- Let's make it a habit!
- Sometimes when we set time aside every week, it's more likely we will just get used to setting aside this time for ourselves. This can help make us more productive and effective in other areas of our lives as well.
- Any day could be the first day to add some joy!

If you're having trouble getting motivated, reach out to us in the CF clinic for additional tips and tricks. Your psychosocial team, Jaclyn (mental health coordinator) and Alexis (social worker), are here to help!



Staying Active During the Summer Months

By Lisa Burns, MD

Summertime is a great time to find an exercise routine that works for you. Did you know that exercise can help improve your physical and mental health? All adults are encouraged to exercise in order to help decrease risk of heart disease, bone disease, diabetes, and cancer. Exercise can also lead to improvements in energy, mood, and can be a great way to spend time with friends and family. For those with CF, exercise has an added benefit of improving lung function by helping to clear the airway of mucus. It can also help to stabilize blood sugars in those with abnormalities in glucose control.

Finding time to exercise may be easier than you think. Guidelines recommend 150 minutes of moderately intense activity a week. This may sound overwhelming, but it can be broken down into small amounts each day. For example, you could take a walk for 10-11 minutes twice a day or take the stairs whenever you have an opportunity.

Tips to developing a successful exercise routine:

- Think of a variety of activities you can do to help you stay interested in your routine.
- Consider enrolling in exercise classes like spin class, yoga, or dance. The energy level of the class may be contagious and the schedule may help you stick to your routine.
- Set small goals and celebrate your success. Make your goals more challenging as you track your progress.

Tips for safe summer time exercise:

- Make sure you stay hydrated and get extra salt. People with CF lose more salt in their sweat than those without CF. You can add a salty snack with your water or drink a sports drink to help get extra electrolytes with your fluid.
- Pay attention to the temperature and humidity outside. Exercising outside in the early morning or evening will be cooler than mid-day.
- If you go to a gym, make sure you wipe down exercise equipment before use to clean away any germs that may be present.
- Make sure to stretch and think about non-weight bearing activities if you have joint disease.

As always, we are here to help. Ask your team about a safe exercise plan for you.



Beat the Heat and Stay Hydrated this Summer!

By Liz Wanamaker, RD

With Virginia's summer heat already in full swing, staying hydrated is important for everyone, especially those with CF. People with CF need more salt with their fluids, especially when sweating more. If you're exercising, working outside, or just sweating sitting still on a humid day (let's be honest, a very common occurrence), you could likely use some additional salt!

A quick and easy way to add extra salt to a drink is adding 1/8th of a teaspoon of salt to a Gatorade or G2.

Interested in trying a different electrolyte product than just Gatorade and salt? Ask Liz at your next clinic appointment or over the patient portal for different brand suggestions!

Don't feel like measuring?

Each one of these packets are 1/8th of a tsp (290 mg sodium)



Eat foods with high water content

Hydrate with the added bonus of nutrients. Try:

- Watermelon
- Citrus fruits
- Berries
- Salad greens
- Cucumbers
- Bell peppers
- Celery
- Tomatoes
- Squash
- Yogurt
- Soup
- Popsicles



Drink other fluids

Hydration doesn't just come from plain water. Try:

- Milk
- Plant-based "milks" (almond, cashew, soy, rice)
- Coconut water
- Seltzer/carbonated waters
- Unsweetened iced tea
- Gatorade/G2

**Note: Although soda and juice are fluids, the high amount of sugar does not make these the best options.*

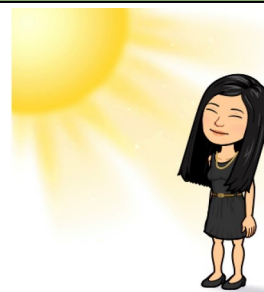
Amp up your water

Get hydrated with the added bonus of fiber, and vitamins. Try:

- Add a splash of your favorite juice to a tall glass of water (or carbonated water)
- Add chopped fruit or vegetables such as cucumbers, berries, fresh mint, or pineapple
- Try water flavoring drops (in the drink aisle at the grocery store)

Vitamin D & Bone Health in CF

By Trang Le, MD – CF program collaborating endocrinologist



Patients with cystic fibrosis are at risk for lower bone density and weaker bones over time, due to factors such as lower body weight, use of steroids, and difficulty absorbing vitamin D. For best bone health, the Cystic Fibrosis Foundation recommends keeping vitamin D levels of 30 ng/mL or above. Staying on top of your vitamin supplementation and pancreatic enzymes can help to maintain these levels. Your CF Care Team does check your vitamin D at least once a year and will help you adjust the vitamin D dose as needed to help you reach this goal. An interesting fact about vitamin D is that it is made from cholesterol in the skin when exposed to sunlight, and as a result, many people will have higher vitamin D levels in the summer than in the winter. 10 to 30 minutes of sunlight exposure, three times a week, while wearing a tank top or short sleeved T-shirt and shorts can provide many people with improved vitamin D levels. An advantage of sun exposure is that it can increase your vitamin D level without having to worry about gut absorption, as with oral vitamins. However, risks of sun exposure include sensitivity or rash for people on certain antibiotics, and with prolonged exposure times more than recommended above, increased risk of sunburn and skin cancer. If you don't have a reason to avoid all sun exposure, taking a short walk outside three times a week may help boost your vitamin D levels (and your mood, since exercise is always helpful!). Otherwise, it is always a great idea to use sunscreen for any longer exposure to sunlight— we can always help with monitoring vitamin D levels and adjusting your daily or weekly supplements to keep your level above 30, and help you maintain a lifetime of healthy bones.

Summer Fun: Traveling with CF!

CF Travel Tips & Tricks

by Campbell Bryan, PAC Co-Chair

Summer may mean more travel and for a CFer this can increase planning and take away a bit of the excitement of a trip. I don't want to admit it, but every time I begin planning a trip, a part of me is bothered by all the planning and packing that will go into it that I almost don't want to travel at all. I recently had to travel more for work and was forced to develop a good system for travel, and I hope it helps all those other traveling CFers out there! My number one trip-planning-help-tool are extra large zip-lock bags. My number two trip-planning-help-tool is my packing list. I wrote it down and review it with every trip, it goes like this:

- Vest and plugs / batteries
- Neb Compressor plugs and tubing

- Neb cup sets
- Antibiotic drugs
- Albuterol/Pulmozyme/Hypertonic
- Oral pills
- Spit cups
- Tissues (or just a roll of toilet paper)
- Nose plugs
- Small dish-soap for washing nebs and reusing them
- Travel letter if airport TSA gives me trouble
- Ear buds/headphones
- A good book

I review every time I prepare for a trip and count out each day's worth of drugs/equipment I will need, and then zip-lock everything up! Hope this helps for your upcoming trip needs - there's nothing more annoying than being on a trip and forgetting your compressor



Above: a look inside Campbell's suitcase!



Left: Ella Balasa, PAC co-chair, nebulizing medication at the Colosseum in Rome, Italy

Additional CF Travel Tips from Genoveva Garcia, RN

- Obtain necessary permits or government authorization. Your CF Clinicians at your request, gladly will provide a letter explaining your medical treatment and necessity.
- Take enough medication to last the length of your trip, preferably on their original labeled containers. Avoid combining multiple medications in the same container.
- Find out common restrictions to destination and avoid those, if possible. Each country has their own guidelines and what it is allowed to cross the border.
- Be aware of your destination's environment and how can affect your health. Take steps to reduce adverse effects and discuss a plan with your Doctor.
- Resources when traveling overseas:
 - The FAA provides guidance for safely taking your assistive devices at <https://www.faa.gov/hazmat/packsafe/TSA-ContactCenter@tsa.dhs.gov> or call 855-787-2227.
 - U.S. State Department: [U.S. embassy websites](#)-The US Embassy can assist providing information about banned and restricted medications of your destination country U.S. State Department: [country information](#)
 - International SOS [Assistance App](#) and [country guides](#)



On May 30th 2019, Vertex Pharmaceuticals announced their plan to submit a new drug application (NDA) for their triple-combination (TC) therapy to the Food and Drug Administration (FDA) by the Fall of 2019. The press release follows final data review from two 24-week Phase 3 studies in people with one *F508del* mutation and one minimal function mutation and from two 4-week Phase 3 studies in people with two *F508del* mutations. This news is highly anticipated by many in the CF community as data from the triple-combination trials not only show improvement upon current modulator therapies (Orkambi and Symdeko), but also showing benefit in CF patients not previously eligible for a modulator therapy.

The trials evaluated the safety and efficacy of two “next generation” modulators (VX-659 and VX-445) in combination with VX-770 (ivacaftor) + VX-661 (tezacaftor). Both TC regimens showed highly similar and positive benefit-risk profiles. Vertex ultimately determined that the VX-445 (elexacaftor) triple combination regimen could benefit the greatest number of CF patients. This decision was based on a detailed assessment of multiple factors, including favorable profiles for safety, tolerability and drug-drug interactions, the ability for co-administration with hormonal contraceptives, and the lack of photosensitivity. VCU was not involved in the VX-659 trial but was involved in the VX-445 trial.

After Vertex submits the NDA for the TC regimen, the FDA will review the application for approval. If approved as described in the press release, the new TC therapy will be available to CF patients with two copies of *F508del* mutation as well as patients with one copy of *F508del* and one minimal function mutation not responsive to modulator therapy. There is no definitive timeline but approval is expected within the next year.

If you have any questions about your modulator therapies or research in general, please contact Ryan at 804-628-3921 or Ryan.Hayden@vcuhealth.org

For more information:

<https://investors.vrtx.com/news-releases/news-release-details/vertex-selects-triple-combination-regimen-vx-445->

Upcoming CFF Events & Updates:

- Our CEO and President, Dr. Preston Campbell, will be retiring this year and Dr. Michael Boyle will be taking over his position in January 2020.
- Vertex Pharmaceuticals Inc. announced last week that it will seek FDA approval of its CFTR modulator VX-445 (elexacaftor) combined with tezacaftor/ivacaftor (Symdeko®). <https://www.cff.org/News/News-Archive/2019/Vertex-Selects-Triple-Combination-With-VX-445-to-Submit-for-FDA-Approval/>
- The Richmond's Finest and Brewer's Ball will be taking place on June 27 at Historic Tredegar from 7-11 pm. If you are interested in attending, information regarding the event can be found at: <https://finest.cff.org/brewersballrva> or by contacting Katherine Layton at klayton@cff.org.
- VA Cycle for Life will be taking place on August 24 at Hardywood Park Craft Brewery: West Creek. If you are interested in participating, information and registration can be found at: http://fightcf.cff.org/site/TR/Cycle/130_Virginia_Richmond?fr_id=7631&pg=entry or you can contact Beth Saladino at bsaladino@cff.org.
- The Xtreme Hike Kickoff is starting off with a training hike on June 29 at Walnut Creek Park near Charlottesville. If you are interested, you can find out more information at http://fightcf.cff.org/site/TR/Hike/130_Virginia_Richmond?pg=entry&fr_id=7636 or contact LaDonna Austin at laustin@cff.org.

Sloane Smith, Event Support Specialist
Cystic Fibrosis Foundation, Virginia Chapter
ssmith@cff.org
(804) 527-1500

