

October 2022

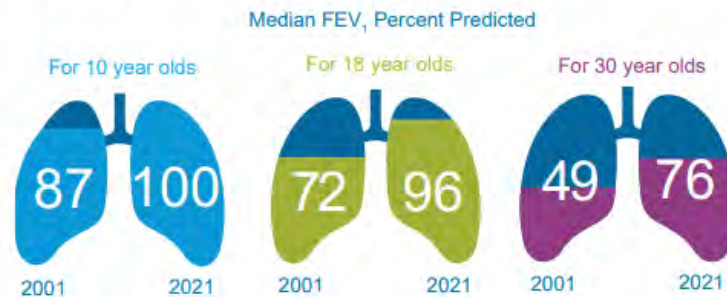
Dear Inova CF community,

2022 is flying by! As things start to “return to normal”, we want to update you on what’s happening at the Adult CF Center.

Here are some other exciting things that are returning closer to normal as well from the CF registry data. Average lung function now is for adults over age 18 is 17-24% better than it was in 2001!

LUNG FUNCTION

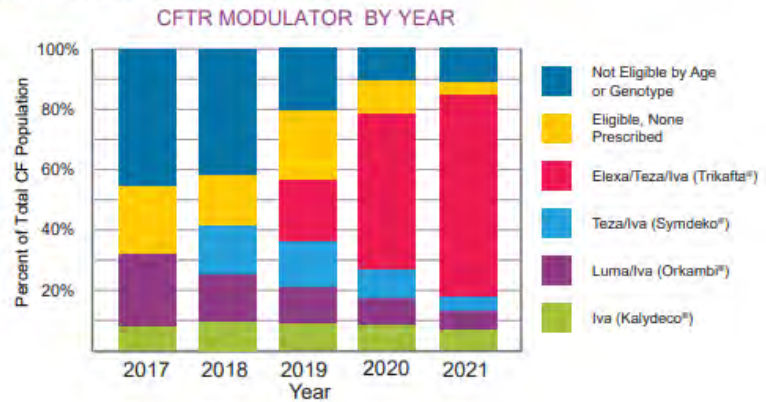
Lung function is a primary indicator of health for people with CF. FEV₁, a measure of lung function, is the Forced Exhaled Volume of air in the first second of an exhaled breath. It is shown as a percent predicted based on the FEV₁ of healthy, non-smoking people of the same age, height, and gender.



Also, the number of people with CF who are using highly effective CFTR modulator therapies continues to increase. Approval for elexacaftor/tezacaftor/ivacaftor is now down to patient between ages 6-11. However, 10% of the population of people with CF continue to not be eligible for modulator therapies because of their genotype. The CF research community continues to work on new therapies until CF stands for “cure found”!

CFTR MODULATORS

The number of people with CF who are using CFTR modulator therapies continued to increase. The expanded approval of elexacaftor/tezacaftor/ivacaftor for children with cystic fibrosis ages 6 - 11 in June 2021 resulted in approximately 1,500 becoming eligible. Ivacaftor was approved for children as young as 4 months in September 2021. More than 23,000 people with CF were taking a CFTR modulator by the end of 2021.



Team Additions/Changes in our Program in 2021:



Dr. Onix Cantres Fonseca is our 2022-2023 Advanced Lung Disease & Lung Transplant Fellow. He started with our team July 2022. He completed his training at the University of Puerto Rico. He worked as faculty and associate program director of the Veterans Hospital in Puerto Rico. He joins us with a wealth of knowledge and wonderful enthusiasm for learning. In his spare time, he enjoys spending time with his furry 4-legged companion.

Gina Collins, RRT MPH is our new CF Respiratory Therapist. She has been working as a respiratory therapist for over 30 years. She is hard-working and sincere. She looks forward to meeting and working with you.



She is a hard-working Therapist. She has been working as a respiratory therapist for over 30 years. She is very hard-getting to know each

Our Growing Inpatient Team

Lauren Marinak, N.P. (left)

Lauren grew up in the Northern Virginia area. In her free time, she enjoys running around town with her 6-year-old daughter.

Michelle Kopp, P.A. (center)

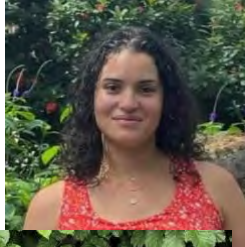
Michelle moved to the area from Boston. She speaks fluent Spanish. In her free time, she likes to spend time outdoors and walk her golden doodle, Stella.

Nikki Sisserson, PA (right)

Nikki moved to the area from Florida because she enjoys the DMV. She enjoys traveling, exercising at Barry's, and riding her Peloton.



APU RN CF Champions – These awesome APU nurses have joined with our quality improvement team to improve all aspects of the care we deliver to our patients.



Lourdes Martinez, RN

Lourdes enjoys traveling, visiting the beach, Zumba dancing and scary movies.

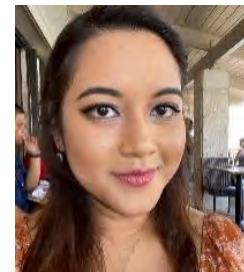


Bella Urcia, RN

Bella enjoys baking sweet treats, traveling with friends and family, and visiting the beach.

Marlyn Vasquez, RN

Marlyn loves experiencing new places and cooking. She is obsessed with Disney!



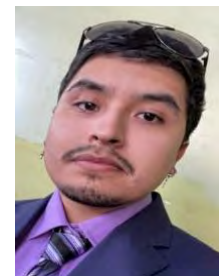
Sueyesha KC, RN

A fun fact about Sueyesha is that she can speak 4 languages!

Our Front-Line Clinic Team

Hector Sejas

Hector is from Bogota, Colombia, but has been in the US since he was 8 months old. He has 2 dogs (Simba and Diego) and loves to read/listen to the news to stay up to date on current events. He also likes going to the gym.



Erick Douglass (LPN)

Erick is a true southerner, born in Georgia and raised mostly in Alabama. In his free time, he likes to smoke meat (mostly ribs and brisket) and get out and bike ride when the weather permits. He is a military spouse and former military brat so traveled all over the world.

Janiece Lacy (LPN)

Janiece also works as a Real Estate agent with Redfin. In loves spending time with her nieces and nephews. She concerts, bowling, hanging with friends and watching Cowboys!



her free time, she also likes going to football. Go

THE REST OF OUR AWESOME TEAM REMAINS THE SAME!!!

COVID-19 Vaccination: We strongly encourage everyone in our adult CF program and their families to receive the COVID-19 vaccine. This includes the updated “bivalent” booster dose. The updated boosters protect against the most recent Omicron subvariants as well as the original strain. Everyone who is fully vaccinated can get a bivalent COVID booster if it has been at least 2 months since their last booster.

We also encourage you to get your annual flu vaccine now.

Even with mask mandates being lifted around the country, masking remains critically important for people with CF and their families to protect themselves from infection.



Inova is requiring vaccination for all staff members. Masks are required for all patients, visitors, and team members in clinic and anywhere on the hospital campus.

- The CF Foundation strongly supports COVID-19 vaccination and has good information on their website at <https://www.cff.org/managing-cf/covid-19-questions-and-answers>
- If you have questions or concerns regarding vaccination, please do not hesitate to talk to the Team!

If you test positive for COVID-19, please make sure to let us know so we can help monitor and guide your care.

Inova Adult CF Program News:

Pharmacy Grant

This year, the CF Foundation sponsored an award designed to help implement outpatient pharmacy services in CF clinics around the country. The grant provides funding to support the hiring of a pharmacist and pharmacy technician to be present in CF clinic and attend NACFC. The pharmacy team will help get medications for our patients as soon as possible (by working on prior authorizations, co-pay assistance, etc.), and review medication interactions.

Clinic Renovations

Our outpatient clinic will be undergoing renovations this fall. The new lay out will include more seating and a more modern look overall. We will also be getting new exam beds in each room. Renovations should be completed by the beginning of 2023.

Why I come to CF clinic

We know life gets busy and CF clinic may have seemed less important recently than in the past. With changes from telehealth to in-person, to telehealth, and now back to in person again, scheduling may have been challenging. As a result, many people have gone longer than usual without being seen in clinic.

“I go to the CF clinic because communicating my needs and wants is much easier in person. Talking in person allows us to fully understand each other and explain our situation in a place where we could get help much easier and much quicker. Knowing where we are as CF patients is very important, because this knowledge helps us make a plan, and go forward and towards the life we want and can live. I also go to the clinic with no reservations because I know that I am always well taken care of, and that they have my back no matter what.” -25-year-old patient with CF

The CF Foundation continues to recommend routine follow-up visits every three months (both pre- and post-transplant), and that is what our program still aims to achieve. However, we have become aware of another pressing issue. Some insurers are requiring that patients have a visit within the prior 12 months for them to approve coverage of CF medications such as Trikafta, Kalydeco, Pulmozyme, Cayston, and TOBI. We don't want you to have difficulty getting your Trikafta and other important medications.

Also, if you have an appointment and need to cancel, please let our team know as soon as possible so we can open those clinic spots to other patients who need to be seen. Thank you so much for your attention to this matter.

If it has been more than 6 months since your last visit or you need to change your appointment, please call **(703) 776-7876** or e-mail cfappointments@inova.org to schedule a visit ASAP. We also encourage you to schedule your follow up visit after your appointment in clinic with our front desk staff, the schedule should be open for up to 6 months in advance.

Primary Care

Since we specialize in CF, we recognize that we are not experts in everything. We recommend getting a Primary Care Physician (PCP) to help take care of health issues such as high blood pressure, high cholesterol, cancer screenings [The CF Foundation recommends that colorectal cancer screening begin at age **40** in people with cystic fibrosis with re-screening every five years], thyroid disease, pap smears, mammograms, and birth control.

A PCP affiliated with Inova is very helpful to share notes and test results. Dr. Gibson (one of our inpatient hospitalists) is working with Inova Primary Care to identify providers interested in partnering with the CF team to provide comprehensive care by providers knowledgeable in CF specific issues and beyond. We are hoping to pilot a collaboration with the Primary Care Team out of Inova Loudon soon, more to come Spring 2023!

Several of the Inova Primary Care locations (i.e. Ashburn) also offer mental health services in their office. This is a great resource if you, like many of our patients, are struggling with navigating the mental health support system.

Here is a link to search for a PCP in your area:

<https://www.inova.org/doctors?specialties=primary-care>

We will continue to take care of all your CF related health issues and work to communicate well with your PCP 😊

NUTRITION



Proper nutrition is associated with better lung function. With CFTR modulators, adults with CF can gain weight more easily. This has resulted in a healthy weight for most people, but 12% are now considered obese as defined by a BMI greater than 30.

ADULTS
MEETING BMI GOALS

65%

Over age 20, the BMI (Body Mass Index) goal is 23 for men and 22 for women.

MEDIAN BMI PERCENTILE
FOR 2 - 19 YEAR OLDS

62

The BMI percentile goal is 50 or greater for children and adolescents.

Nutrition Corner: Snacking with Shannon!

As fall begins and schedules fill up, it's easy to skip meals or reach for easy fixes. Mix up a batch of these protein bites that will keep in your fridge. These supply an easy source of protein, good carbs and healthy fats to keep you from relying on the drive thru or other unhealthy options. Bonus, these contain about 9g of fat per bite and are the perfect serving to take with your Trikafta dose!

Protein Energy Bites

Ingredients:

- 1 ½ cups creamy peanut butter
- ½ cup honey
- 1 1/3 cup old fashioned rolled oats
- ½ cup vanilla protein powder (or chocolate!)
- 1/8 teaspoon salt
- ½ cup mini chocolate chips

Instructions:

1. Add the peanut butter, honey, oats, protein powder, salt and chocolate chips to a mixing bowl. Mix with a rubber spatula until the batter is combined.
2. Use a mini cookie scoop or spoon to drop 1 inch bites onto a covered cookie sheet.
3. Roll the bites with your hand into a ball.
4. Place the cookie sheet in the fridge for 1 hour and then transfer to a Ziploc bag and store in the freezer.

Food and Friends

Our CF program has partnered with the CFF and Food & Friends to offer a program to bring more food resources to our patients and their families. You may be eligible to have prepared meals or groceries delivered to your home.

If you are interested in learning more about these programs, please reach out to Shannon Spada Shannon.Spada@inova.org or Elizabeth Elizabeth.Davies2@inova.org.

“Food and Friends has allowed us to not have to decide what’s for dinner and alleviates decisions that need to be made about food shopping, recipes and actually making the meals”

Inova CF Food Pantry

Our CF Food Pantry continues to be an excellent resource for our patients who may be experiencing food insecurity. Food insecurity is the lack of reliable access to a sufficient quantity of affordable, nutritious food. Over ¼ of people with CF have food insecurity. This is more than double the level of food insecurity in the US (11.1%). Improving food security is associated with better dietary intake and may lead to better disease management, lower health care costs, and overall better health.

- We want more people to take advantage of this important program! There is no income requirement and please don’t hold back because you think someone else has it worse off than you do. **If getting some groceries makes your life easier and allows you more time/energy/resources to spend on your own care, then you should speak up.** There are plenty of groceries to go around!!!
- If you are interested in making a monetary donation to the CF Food Pantry please contact Katie Coyle with the Inova Foundation, Katie.Coyle@inova.org.



We would like to highlight our fantastic teen volunteers who do our grocery shopping for us. Siblings Emily and Colin Wadlow have been keeping us stocked with an amazing assortment of items for over 2 years. A huge thank you to Emily and Colin for their help!

CF Support Groups

Some of our patients and family member have expressed an interest in joining support groups that are available for people with CF and their families. Below are support groups that are available through various national CF organizations. Please see their websites for more information.

CFRI Support Programs

(<https://www.cfri.org/education-support/psychosocial-support-programs/>)

To participate, please send an email to CFRI (sbrants@cfri.org) to request the registration link. Please allow 3-4 hours before the meeting to register.

- **Caregivers Support Groups: Third Tuesday of Every Month**
Parents of children with CF: 8:00 pm – 9:00 pm EST

Parents/Spouses/Partners of Adults with CF: 9:00 pm – 10:00 pm EST
- **Online Support Group for Adults with CF: Third Monday of Every Month, 9-10:30pm EST**
- **Navigating Grief to Growth – Bereavement Support Group: First and Third Tuesday of Every Month, 8pm EST.** For those who have lost someone they know to CF
- **Post-Transplant Support Group: Fourth Wednesday of Every Month,**
- **Support Group for the Spanish-Speaking CF Community: Second Wednesday of Every Month, 8-9pm EST**

Attain Health Peer Engagement Virtual Groups

Please visit their website (<https://attainhealth.org/peer-engagement-groups>) for more information about the groups listed below.

- Adults with CF
- Ladies Night
- “Inhale Melanine, Exhale Power”
- CF Fighters for Recovery and Freedom
- Moms with CF
- Solid Ground – A Women’s Prayer and Bible Study Group
- Young Adult Group
- LGBTQ & Spirit Social Hour

CF Peer Connect

- One on one peer mentoring offered through the CF Foundation to help people with CF and their families navigate different life transitions. For more information, please visit <https://www.cff.org/get-involved/cf-peer-connect> .

Keep on moving, exercise is good for the soul and the lungs!

“If exercise could be purchased in a pill, it would be the single most widely prescribed and beneficial medicine in the nation.” – Robert H. Butler

Bri O’berry, our CF Physical Therapist, is piloting an Inpatient exercise program. This inpatient exercise program is intended to be self-guided and to help you meet your daily activity goals. It includes a walking program, muscle strengthening exercises, and flexibility exercises. If you ever find yourself in the hospital, make sure to remind the team to ask for a Physical Therapy consult to participate in the exercise program.

Another great way to incorporate more exercise into your routine is the Beam website. (<https://beamfeelgood.com/cystic%20fibrosis>). This site is free to all patients with CF through the end of 2022. They have a variety of programs tailored to varying abilities for people with anywhere from normal lung function to advanced lung disease.



The CF Foundation also offers a free online program of yoga classes for people with CF and their families for a variety of yoga experience and skill backgrounds (including brand new to yoga).

<https://www.youtube.com/watch?v=Z46K7kteiaE>



Interested in participating in research?

To find CF clinical trials you may qualify for in the MD/VA/DC area, go to <https://apps.cff.org/trials/finder/?search>

Some enrolling studies in our area are listed with more info available online:

- BiomX BMX-04-001 Part 1 and 2: This study is testing the safety and tolerability of nebulized BX004-1, a bacteriophage drug intended to treat infections in the lung. Bacteriophages are specialized viruses that kill very specific bacterial strains.
- Aridis AR-501-001 MAD cohorts: This study is testing inhaled AR-501, a drug intended to treat infections in the lung. Multiple doses will be tested in both healthy adults and adults with CF
- Armata AP-PA02-101 MAD: This study will look at the safety and tolerability of inhaled AP-PA02, a bacteriophage drug intended to treat infections in the lung.
- ABATE-IP-18: This study will look at the safety and tolerability of IV gallium, a drug intended to treat lung infections
- Mayflowers: This observational study (no interventions, just monitoring) will evaluate the effects of CFTR modulators on women with CF during and after pregnancy
- Predict: This study will evaluate the current standard of diagnosing nontuberculous mycobacterium (NTM) in people with CF
- CHEC-OB-17: This study will look at sweat chloride concentration in people who are currently taking CFTR modulators.
- Sound Pharma SPI-3005-501.2: This study will test the safety and tolerability of SPI-1005, a drug intended to prevent and treat hearing loss caused by aminoglycosides (a type of antibiotic)

Observational study of adults with Cystic Fibrosis for Colorectal Cancer screening (NICE-CF)

What: Multi-centered observational study will compare stool-based testing to colonoscopy for colorectal cancer screening in people with CF.


Who: Adults with CF 40 years of age or older, without history of transplant or Adults with CF age 30 or older who have had a transplant. Adults must be due for routine colon cancer screening.

Why: Assess for potential alternatives to colonoscopy

Funding Agency: Cystic Fibrosis Foundation

Sponsor Site: Saint Louis University

Contact for more information: eenright@uw.edu or CFF clinical trials finder: Colon cancer/NICE *



* Side information is not to be used for direct patient marketing.

PFAB (Patient Family Advisory Board) Corner

Do you have a unique perspective? We want to hear your thoughts on CF Care at Inova Fairfax! Join us the Patient and Family Advisory Board (PFAB)!

The PFAB at Inova Fairfax Hospital's Cystic Fibrosis Center is seeking new members for 2023. Come join us!

The PFAB is a partnership between patients, family members, and the CF Care Team. Our mission is to bring the patient and family perspective to Inova, so that CF patients consistently receive high-quality medical care in an environment of caring, respect, and patient safety.

The PFAB is a collegial and diverse group of patients and family members as well as clinic staff. We are looking for new members, especially CF young adults and those from underrepresented communities. PFAB members attend a monthly meeting via Zoom, actively contribute to the conversation, and collaborate on smaller spinoff projects of their choosing. The time commitment is approximately 1-2 hours a month.

In 2021-22, some of the initiatives the PFAB worked on included: a pilot program partnering with Inova primary care physicians to develop a cadre with improved understanding of CF, "What I Wish My Doctor Knew About CF" factsheets, improvements to inpatient pharmacy services to reduce delays in administering medications, and ongoing education sessions for hospital staff.

We would love to hear from you and to have you drop in on a meeting to check us out. Our email is inovacfpfab@gmail.com. Interested in joining? Please reach out to Elizabeth Davies-Wellborn at Elizabeth.Davies2@inova.org.

Opportunities:

- **Advocate for Legislation and Your Health!**

The Cystic Fibrosis Foundation has robust and highly regarded national grassroots advocacy program. Currently, they have a very high Congressional priority — pass the Pasteur Act during this Congress. The Act is a bipartisan proposal that will support the development of new antibiotics and promote appropriate use of existing ones, a critical issue for those with CF as well as many others in the country.

Sign up for the Foundation's advocacy alerts. This is an easy and direct way to communicate with your Congressional members by email, text or social media. Importantly, you can decide if you wish to act on an issue-by-issue basis. To sign-up, simply text **FIGHTCF to 96387** or go to <https://act.cff.org/tYteTfQ>

For more information on the Pasteur Act, here is a link to read the Foundation's letter of support for the Pasteur Act.

<https://www.cff.org/sites/default/files/2021-10/CF-Foundation-Letter-of-Support-on-PASTEUR-Act.pdf> as well as an August article from

PewTrusts <https://www.pewtrusts.org/en/about/news-room/opinion/2022/08/12/without-new-antibiotics-the-superbugs-will-keep-winning>

If you would like to learn more about the Foundation's significant policy work, check out this link, <https://www.cff.org/about-us/our-public-policy-work>

- **We are a clinical trial site for the Vertex-121** new triple modulator which is being studied against Trikafta. We are currently enrolling for people with one copy of Delta F508 mutation and another mutation from a specific category. Please talk to the team if you are interested in more information about this trial as it is likely to fill quickly.
- **North American Cystic Fibrosis Conference (NACFC) is November 3 – November 5, 2022.** Register (<https://hopin.com/events/virtual-nacfc-2022/registration>) for the free Virtual Sessions if you are interested in watching. Our team will also report back with updates from the conference later this year!

We wish you continued health and well-being for 2022. As always, it is a privilege to be in your lives and to help take care of you.

Your Inova Adult CF Care Team,



A collection of handwritten signatures from the Inova Adult CF Care Team. The signatures are arranged in several rows and include the following names and titles:

- Aj Singh
- Alan Nyquist
- Kate Gibson
- Rawson Marinak, NP-C
- A. Whitney Brown
- Micahella Kopp, PA-C
- Danyela
- Mikhi Srinivasan, PA-C
- Meg Frey, NP
- Jessica C., NP-C
- Brittany, PT, DPT
- Cheryl, RRT
- Michelle Schuffler, RN
- Sharon Spade, RN
- Morgan Wahl, RN
- Melissa Jones, RN
- Cybil Davis-Wellman, MSW
- Thir King
- U. A. A.
- Claire Collins
- Shambhu Arora, NP-C

We are so excited to spend another year with you!