

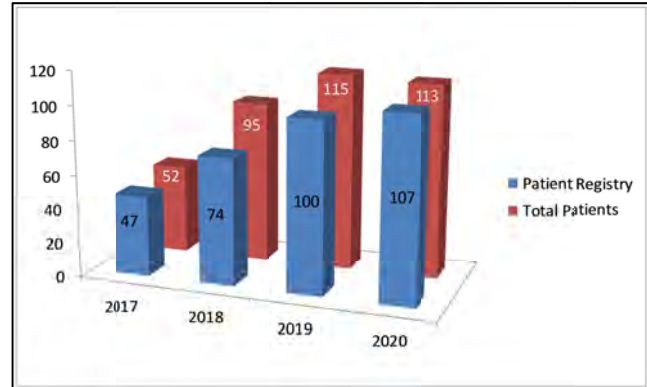
March 5, 2021

Dear Inova CF Community,

We hope 2021 is going as well for you as it can be under the circumstances! We wanted to take an opportunity to share with you some important information regarding your CF program.

The CF Center at Inova Adult Program maintained its size in 2020. We did not experience the growth seen in the two prior years, perhaps in part, due to the pandemic. We currently care for around 113 adults, 107 (95%) of whom are enrolled in the national CF Patient Registry. In terms of CF patient distribution, 25 (22%) of our patients have advanced lung disease, 18 (16%) have had a lung transplant, and the remaining 70 (62%) represent a more standard CF population.

INOVA ADULT CF
PROGRAM 2020
N=113



Clinic Updates

We continue to offer both in person clinic visits and telemedicine visits and will do so for the foreseeable future:)

- For in person visits, you will receive a COVID Screening Call 1-2 days before your appointment
- When you enter the hospital, you will be given a facemask and have your temperature taken
- One companion is allowed to attend the visit with you, they must be 18 years or older
- Pulmonary function tests are being performed in negative pressure rooms for safety

We have a new email for new or existing Inova Adult CF patients to streamline scheduling clinic or telemedicine appointments. cfappointments@inova.org The CF scheduler is Rosa Fuentes who will be monitoring this email.

To contact Rosa directly, rosa.fuentes@inova.org; phone: 703-776-7876.

Hospital Updates

Currently, for infection control, visiting hours during hospital admission are from 1-5pm and limited to 1 visitor per day. Visitors must be 18 years or older. See our (updated) Admission Tip Sheet in this mailing for more details on what to expect during a hospital admission.

Program Accomplishments for 2020

- Educational programs on CF were co-presented to different parts of the hospital by CF Adult Program Staff and patient members of the Patient Family Advisory Board (PFAB)
 - Pulmonary Inpatient Unit (3), Emergency Department (1) in 2020
- Two quality improvement abstracts and posters were presented at the virtual North American CF Conference
 - 1 authored by our CF hospitalist Dr. Gibson & 1 authored by an adult PFAB member with CF

- Melissa Bowen (our CF nurse coordinator) had an abstract on the impact of Trikafta on people with advanced CF lung disease accepted for podium presentation at the American Thoracic Society International Conference (presented virtually in poster format due to the pandemic)
- We met diligently and weekly as a CF QI Team and are particularly proud of the following:
 - 1) We created hospital admission informational folders for each person with CF admitted to the inpatient pulmonary unit. We hope to expand this to the CTU-N (post-transplant) unit soon.
 - 2) We mailed an Adult CF Program newsletter to patients in January & July 2020
 - 3) We hosted 4 webinars to update our patient community on COVID-19, one of which was co-hosted by the PFAB and featured 3 patient speakers (and recently one on vaccination on 2/25/2021 as well)
 - 4) We hosted our 3rd annual North American CF Conference (NACFC) Webinar Update to relay the highlights of NACFC 2020 to our patients and families in December 2020
 - 5) Using our mental health funding, we launched Mental Health Programming (online seminars) for our CF population:
 - Wellness webinars began in October 2020 (Topics: Resilience; Anxiety as a Superpower) and will continue on a regular basis
 - Mindful Movement program on January 28, 2021 which will start as a series on March 18, 2021
 - Small group 2-month discussion series (first group started on Feb 2, 2021)

Inova CF Food Pantry

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 created an Inova CF Food Pantry in March 2020. We have received generous support from Giant Foods and General Dynamics, as well as from patients, community members, and our own team members.
- Volunteers from *The Church of the Holy Comforter in Vienna* do our food shopping so that we can have healthy and yummy snacks and groceries available in clinic for pick-up at appointments or in between appointments.
- **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/money to spend on your own care, then you should speak up. There are plenty of groceries to go around!!! Feel free to **contact Elizabeth at Elizabeth.Davies2@inova.org**.
- 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.

A Message from the Patient Family Advisory Board...

In June 2019, a few CF patients and care team members started a CF Patient Family Advisory Board (PFAB) to help improve the CF patient experience and drive quality improvement through education, outreach, and dialogue. Some initiatives we worked on this past year (certain webinars, providing a patient perspective at Inova CF education programs, tip sheet and welcome letter for the admission folders) are mentioned elsewhere. But in addition we developed a respiratory therapy preference card for hospitalized CF patients to fill out so that the respiratory therapists will know the patient's preferred time and method for nebs and airway clearance. Look for this in your admission folder. And in December 2020, on behalf of all Inova CF patients, we provided breakfast for the CF care center staff to thank them for all the time and energy they devote to caring for our health; knowing this was more challenging this year due to

COVID-19. For 2021, we have some ideas for improving the patient experience at Inova but if you have any suggestions or are interested in joining the PFAB please send us an email at inovacpfab@gmail.com. The PFAB meets once a month virtually and you can always reach out to Elizabeth Davies-Wellborn (SW) for more information.

Research Corner

We are still looking for people to enroll in a six-minute walk study to see the effects of a new device called the TAV (Tidal Assist Ventilation) on breathlessness and ability to exercise in people with more advanced CF lung disease. The study involves 3 total visits (1 for full PFTs and 2 visits with 2 six-minute walk tests with the TAV device). All studies are free of charge and some reimbursement for your time/travel is provided. **If your FEV₁ is below 50% predicted and you are interested in participating in this research, please contact Ashley “Claire” Collins at Ashley.collins@inova.org or talk to Dr. Brown.**

Cystic Fibrosis Patient Registry

We are happy to report that more than 95% of our patients are participating in the national CF patient registry. This registry provides data about individuals with CF on a national level to influence decisions made by the CF Foundation on research and patient care priorities. It also allows us to receive financial support from the CF Foundation to ensure great multi-disciplinary care. It also helps track data on the individual level so we can see trends over time and share them with you. For those not enrolled, please consider and we are happy to tell you more!

Staff Corner

Erin Lopynski, RDN has left our CF program to pursue full-time private nutritional consulting after 2 years of great work with us. We are sad to see her go but wish her all the best in her practice.

We are excited to welcome our new CF dietitian, Shannon Spada, who started on February 24th. Erin is working with Shannon to get her settled in and we look forward to you meeting Shannon soon.

Dr. Anju Singhal (year-long advanced fellow 2020-2021) will be staying with us as a full attending physician and Associate Director of the Adult CF Program in July 2021.

Staying Healthy, Active, & Happy

Small Groups with Claudia

If you are interested in joining a small group, 5-week series to connect with others with CF and gain new coping skills related to anxiety and resilience, please contact Elizabeth, Elizabeth.davies2@inova.org for more information.

Mindful Movement Series

We have partnered with a local group to bring you a 12-week mindful movement (sprinkled with some yoga) series. No previous yoga experience is required. This series is not about being watched or your exercise skills, but about gaining skills for stress reduction. Series begins Thursday, March 18 from 7-8pm and will run weekly for 12 weeks. Totally free! You can drop in for one session or attend all 12 – your choice. Your family members are welcome to join as well. Look for more information in an upcoming email.

Get a Free 12-Month Subscription to the *Ten Percent Happier* Meditation App

Ten Percent Happier has generously provided our CF clinic with a free 12-month gift subscription for each of our patients. Go to <https://app.tenpercent.com/redeem/register> and enter INOVACARECENTER (all caps). More information about 10

Percent Happier can be found on their app or website <https://www.tenpercent.com/>. Please reach out to Elizabeth.davies2@inova.org if you are having any issues redeeming this gift subscription.

Free Online Exercise Classes--- BEAM

Adults with CF can take advantage of Beam, which offers on-demand sessions and live classes with specialist fitness instructors who can adjust exercises specifically for people with CF. The Foundation is offering free membership to Beam through the end of 2021. <https://beamfeelgood.com/cystic-fibrosis>

Announcements

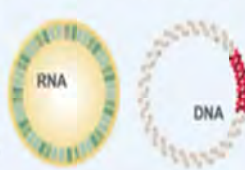
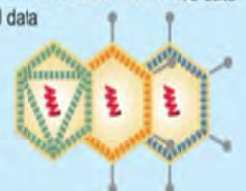
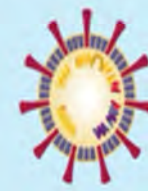

Would you like a home spirometer to check lung function at home? The CF Foundation is sponsoring a program to provide every person with CF enrolled in the CF Registry with a free home spirometer. This helps you keep track of your lung health and makes our telemedicine visits more productive with this information. Email quyen.duong@inova.org to request one and it will be mailed to your home. She can also assist you getting started with device if needed.

HOT TOPIC!!!! COVID-19 Vaccine Information

We recommend COVID-19 vaccination for our patients.

As of February 26, 2021, there are now three vaccines (Pfizer, Moderna, Johnson & Johnson) that are effective in preventing infection with COVID-19 that have been granted emergency use authorization (EUA) by the FDA.

See below for information on how these and other vaccines in development work:

<p>DIFFERENT TYPES OF VACCINES</p> <p>There are several types of vaccines currently under development for COVID-19, each with different potential strengths and weaknesses.</p>	<p>NUCLEIC ACID VACCINES</p> <ul style="list-style-type: none"> ➢ New type of vaccine that uses fragments of mRNA or DNA to produce an adaptive immune response through the host cells, producing copies of that target antigen ➢ Elicits both antibody and cytotoxic T-lymphocyte responses ➢ Can scale up and produce quickly ➢ Expensive & booster doses likely needed ➢ >90% efficacy in initial phase 3 data from Moderna, Pfizer <p>Vaccines in development</p> <ul style="list-style-type: none"> ➢ Moderna ➢ Pfizer ➢ Inovio ➢ CureVac ➢ Sanofi/Translate Bio 	<p>VIRAL VECTOR</p> <ul style="list-style-type: none"> ➢ Uses modified non-coronaviruses (adenoviruses, vesicular stomatitis virus) expressing SARS-CoV-2 spike protein ➢ Elicits both antibody and cytotoxic T-lymphocyte responses ➢ Potential safety concerns in immunocompromised patients ➢ Host immunity to the viral vector may reduce efficacy ➢ 82% efficacy with two doses from AstraZeneca/Oxford data ➢ 66%-85% efficacy from J&J data <p>Vaccines in development</p> <ul style="list-style-type: none"> ➢ Johnson & Johnson ➢ CanSinoBIO ➢ Merck ➢ AstraZeneca/Oxford 
	<p>INACTIVATED VACCINES</p> <ul style="list-style-type: none"> ➢ Uses a killed version of the virus to generate immunity ➢ Elicits neutralizing antibodies without a cell-mediated response ➢ Can be safely given to immunocompromised patients ➢ Proven vaccine technology already in use for several diseases (eg, hepatitis A, influenza, polio, rabies) ➢ Booster doses likely needed <p>Vaccines in development</p> <ul style="list-style-type: none"> ➢ Chinese Academy of Medical Sciences ➢ Wuhan Institute of Biologic Projects ➢ Sinovac 	<p>PROTEIN</p> <ul style="list-style-type: none"> ➢ Uses recombinant viral proteins to induce immune response ➢ Elicits neutralizing antibodies without a cell-mediated response ➢ Can be safely given to immunocompromised patients ➢ Proven vaccine technology already in use for many diseases (eg, hepatitis B, HPV, pertussis, herpes zoster) ➢ Booster doses likely needed <p>Vaccines in development</p> <ul style="list-style-type: none"> ➢ Sanofi/GSK ➢ Novavax ➢ Walter Reed Army Institute of Research (WRAIR) 

Details on mRNA vaccines (Pfizer, Moderna):

Both of these vaccines use mRNA technology. Unlike many vaccines that use a weakened or inactive version of the virus to stimulate an immune response, mRNA vaccines do not contain any live virus so there is NO risk of it causing COVID-19. The mRNA never enters the nucleus of the cell and does not affect a person’s DNA. The body contains enzymes that break down mRNA quickly, reducing chances for long-term side effects.

Both vaccines require a series of 2 shots (21 days apart for Pfizer, >28 days apart for Moderna). The second “booster” shot is necessary to help develop full immunity.

Both vaccines together have been administered to over 70,000 trial participants. The Pfizer vaccine is approved for people over the age of 16, and the Moderna vaccine is for individuals 18 and over. The main side effects after receiving the vaccine were injection site reactions, fevers, muscle aches, headaches, chills and joint pains that resolved within 1-2 days of vaccine administration. These side effects were more common and noticeable after the second dose.

Both vaccines appear to reduce the risk of infection with COVID-19 by ~95%. For context, most experts had hoped for a vaccine that was at least 70% effective. The 95% efficacy of the vaccine is comparable to the effectiveness of the chickenpox (92%), MMR (97%), and polio vaccines (99%).

Details on the Johnson & Johnson vaccine: (adapted from the NY Times article February 27, 2021)

The Johnson & Johnson vaccine, like the other two, is based on the virus’s genetic instructions for building the spike protein. But unlike the Pfizer-BioNTech and Moderna vaccines, which store the instructions in single-stranded RNA, the Johnson & Johnson vaccine uses double-stranded DNA. The researchers added the gene for the coronavirus spike protein to another virus called Adenovirus 26. This modified adenovirus can enter cells but can’t replicate inside them and should not cause illness.

Adenovirus-based vaccines are more rugged than mRNA vaccines. DNA is not as fragile as RNA, and the adenovirus’ tough protein coat helps protect the genetic material. As a result, the Johnson & Johnson vaccine does not require ultra-cold storage and be refrigerated for up to three months.

The phase 3 clinical trial of the vaccine enrolled a total of 43,783 participants ages 18 or older. The trial was conducted in eight countries across three continents (including places with the B.1.351 variant). Overall, J&J's single shot was 77% effective at preventing severe disease two weeks after immunization, reaching 85% effectiveness against severe disease starting four weeks after vaccination...in a single shot.

Distribution of COVID-19 vaccines in the United States is guided by the Centers for Disease Control vaccination priority groups:

Phase 1a	Phase 1b (ongoing)	Phase 1c (ongoing)
Health care workers	Adults 75+	Adults 16-64 with high-risk medical conditions (CF)
Long-term care facility residents	Frontline Essential workers (first responders, education, childcare, food & agriculture, corrections officers, transportation)	Adults 65-74 Other Essential Workers (construction, finance, IT, communication, public health workers)

*Caregivers and family members are vaccinated according to their own risk group, not patients’ risk group. Each state has its own variation on these priority groups.

Commonly asked questions about COVID-19 vaccination:

- **Where will I get it? (put out as many feelers as possible)**

- 1) Register with your local county health department (see below)
- 2) Check with your primary care doctor to see if they're vaccinating in their office (most are not unfortunately)
- 3) Check websites of national pharmacy chains (CVS, Walgreens, Walmart, Safeway, etc.).
- 4) Go to CDC VAMS website and search by zip code
- 5) We will alert you if we receive vaccine supply and are able to vaccinate you through our program

Health Department /Vaccine Information Links:

Virginia: <https://vaccinate.virginia.gov/> (except Fairfax County)

Fairfax County: <https://www.fairfaxcounty.gov/health/novel-coronavirus/vaccine>

DC: <https://coronavirus.dc.gov/vaccine>

Maryland: <https://covidlink.maryland.gov/content/vaccine/>

West Virginia: <https://dhhr.wv.gov/COVID-19/Pages/Vaccine.aspx>

- **Which vaccine should we get?**

Unless you are a transplant patient or on immunosuppressant medication, you should get the one that is available to you first to get protection as soon as possible.

If you are taking immunosuppressive medications, then we would feel most comfortable with you getting Pfizer or Moderna as the J&J vaccine uses an adenovirus vector which has potential safety concerns in those with very compromised immune systems.

- **Will we need to get a COVID-19 shot every year like the flu shot?**

We currently do not know how long immunity from either of the vaccines lasts as they have only been studied for less than a year. Data on antibody levels over time is being collected on the clinical trial participants which will help us know if additional doses will be necessary in the future.

- **Should people who had COVID-19 infection get vaccinated?**

The studies included individuals who recovered from COVID-19 infection, thus it is recommended that even people who had COVID-19 should receive the vaccine when it is available. For patients who received monoclonal antibody treatment for COVID-19, it is recommended that they wait 3 months after the date of the antibody infusion to be vaccinated to ensure the body's full response to the vaccine.

- **Do I still need to socially distance after getting both doses of the vaccine?**

Yes, once vaccinated, we still need to continue universal mask wearing, hand washing, and social distancing regardless of vaccination status.

Staying Connected

Check your email for announcements and offerings from our program. Email is the primary way that we keep you up to date on opportunities and announcements for patients and families. **If you do not think you are on our email list and would like to be included, please let someone on the care team know.**

As a reminder, we do have an Inova Adult CF Program Facebook Group. If you're interested in joining, email Elizabeth at Elizabeth.Davies2@inova.org to get an invite.

Ways to give back to our program:

Patient Assistance Fund. This fund was created to help patients who have unmet financial needs related to their medical care. It is not for direct medical expenses but is used to help with other expenses related to traveling to the center for medical care. This includes things such as gas cards, food vouchers and accommodation etc. If you wish to contribute specifically for this cause, then please designate it to "The Lung Fund" (with patient assistance listed in the memo section).

Cystic Fibrosis Nutritional Support Fund (includes the Food Pantry). This fund was started by one of our generous CF patients and her family. It provides snacks and supplements in clinic as well as groceries to support for those who have food insecurity at home. Please contact Dr. Brown or Katie Coyle from the Inova Foundation at katie.coyle@inova.org if you're interested in donating.

Mark Your Calendars: Important Dates:

- Start of the Mindful Movement Series – March 18, 2021
- Webinar on Exercise in CF by Quyen and Bri- March 24, 2021
- North American Cystic Fibrosis Conference (NACFC) – September 30-October 4, 2021
- COVID-19 Vaccine- ASAP!!!!

Thank you, as always, for your support and confidence in our program and our community.
It is truly a privilege to be part of your lives.

Best wishes for a happy and healthy 2021,

Inova Adult CF Care Team
Cystic Fibrosis Center at Inova

New Adult CF Team Members



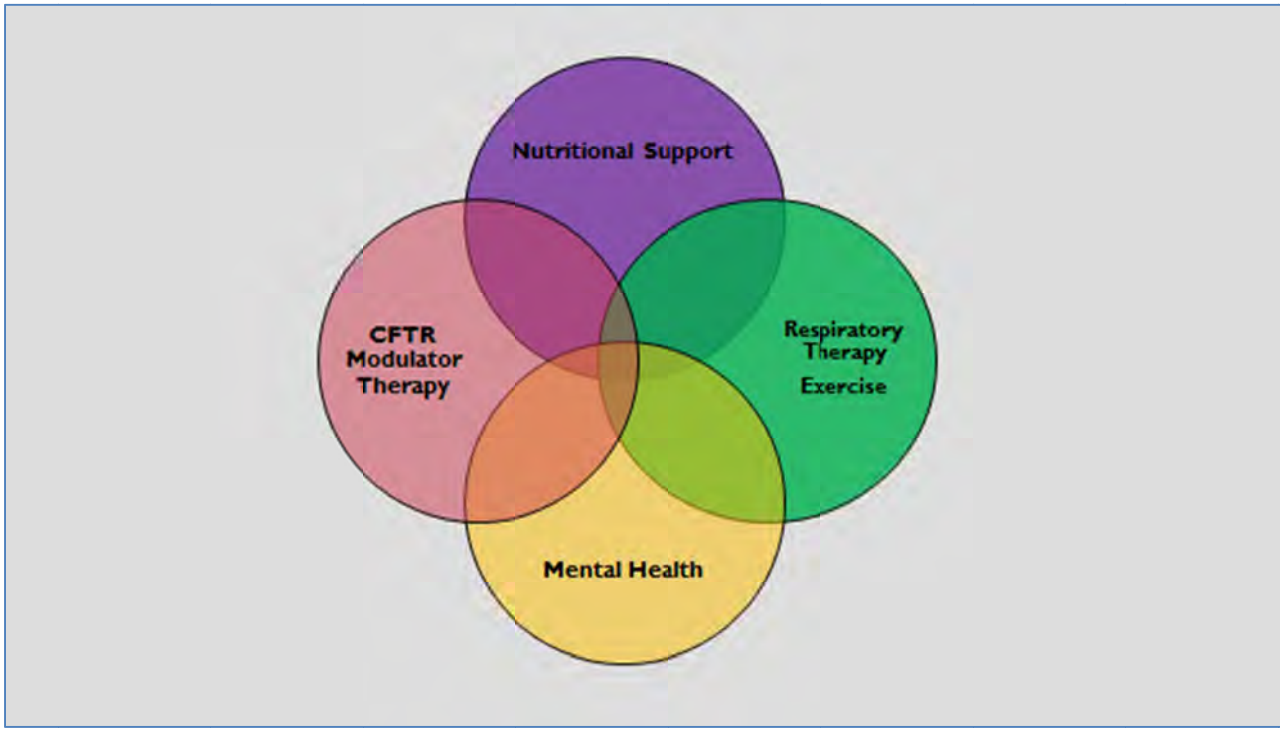
Anju Singhal, MD: New Associate Program Director for Adult CF



Shannon Spada, RDN: New CF Dietitian



We are grateful to have such a strong multi-disciplinary team!



THE INOVA ADULT CYSTIC FIBROSIS TEAM

CF Physicians:

A. Whitney Brown, MD
Christopher King, MD
Shambhu Aryal, MD
Kareem Ahmad, MD
Oksana Shlobin, MD
Steve Nathan, MD
Vik Khangoora, MD
Anju Singhal, MD

CF Hospitalist: Kate Gibson, MD

Inpatient Advanced Practice Providers:

Lauren Marinak, NP
Nikki Sisserson, PA

CF Program Nurse Coordinator:

Melissa Bowen, RN, BSN, MPH

Pre-Transplant Nurse Coordinator: Patricia Jackson, RN, BSN

CF Social Worker: Elizabeth Davies-Wellborn, LMSW

CF Dietitian: Shannon Spada, RDN

CF Respiratory Therapist: Quyen Duong, RRT

CF Physical Therapist: Brianne O'Berry, DPT

Clinic Nurse Practitioners:

Jessica Chun, NP
Meg Fregoso, NP

Post-Transplant Nurse Coordinator:

Michelle Schreffler, RN, BSN

Advanced Lung Disease Inpatient Nurse Coordinator:

Morgan Wahl, RN