

UNC ADULT CF CENTER NEWSLETTER

WELCOME BACK!

A MESSAGE FROM THE DIRECTORS

The last 8 months have been full of challenges for everyone! Fortunately, our patients have protected themselves well during the COVID pandemic, and our CF Clinic and research teams have worked hard to develop new ways of delivering safe, quality healthcare and continuing our critically important research mission.

As the pandemic continues, we just wanted to remind you to stay engaged with your routine healthcare. The CF team is here for you, virtually and in person. As always, appointments may be obtained by calling the Pulmonary Clinic (974-984-5703) and specifying if you want a Telehealth or face-to-face visit. Remember that some problems cannot be handled with a video visit and require an in-person visit. Because we are confident that the measures we have implemented in the clinic make in-person visits extremely safe, we would like to encourage you to conduct your quarterly visits in person, at least every other visit (every 6 months), using video visits between these appointments if things are going well (and only if you prefer this visit type). Of course, as COVID conditions change, we will again pivot towards more remote visits as needed – please reach out to discuss what is best for you! Finally, don't forget to keep up with your home spirometry measurements to ensure you're staying well (and let us know if you still need a device)! One last reminder: remember to stay safe and cautious over the upcoming holidays. Small social gatherings appear to be a major source of COVID transmissions currently, and we will all have to avoid the temptation of letting down our guards.

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WELCOME BACK MESSAGE (CONT.)

WHAT TO EXPECT DURING AN IN-PERSON VISIT:

All patients are screened for COVID-19 symptoms over the phone at the time that they make their appointment. Once a patient enters the clinic building at Meadowmont, they are screened again by a greeter who asks them about COVID-related symptoms. Anyone with suggestive symptoms will be redirected to get COVID testing done (at our Respiratory Diagnostic Center). If you have no COVID symptoms, you will be given a sticker that indicates you have passed the screening and will be provided a mask if you do not have your own. In our clinic itself, you will see a waiting room with plenty of space for physical distancing. Our front desk staff will check you in, and you will be escorted quickly to either the PFT lab or to a closed clinic room. All of the clinic staff and providers will be using "Universal Pandemic Precautions", which includes gown, gloves, mask and eye protection. We have very thorough cleaning processes after each patient visit and at the end of the day.

CONCERNING CF RESEARCH:

While COVID-19 slowed the pace of all clinical trials, we are rapidly increasing research activities and are currently opening new clinical trials. Accommodations are being built into every CF trial to ensure your safety. Appropriate COVID screening procedures and protective equipment will be used to protect all participants. We hope you will consider the important studies being done to address new ways of treating CF infections, determining which specific therapies are still useful after starting Trikafta™, and testing of CF therapies that are designed for anyone with CF, regardless of your CFTR mutation. There is a lot left to be done, and we can't do it without you! If you are interested in learning about current studies, please call our research unit (984-974-9198) and go online to view the CFF "[Clinical Trial Finder](#)", where you can search for studies that match your requirements, or visit our [webpage](#).



AN EXCITING ANNOUNCEMENT

You might have heard that our CF Clinic will be **moving next year** to a brand-new building off of 15-501, near I-40. The **UNC Eastowne Medical Office Building** will include adult medical clinics from nearly every specialty, radiology and laboratory services, and an outpatient pharmacy **all in one location**. This building will also house a clinical research unit where study visits will take place. We are very excited to introduce you to this new facility **early in 2021!**

HOW TO HAVE A SUCCESSFUL VIRTUAL VISIT

We do our best to mimic in person clinic visits. This works much better if you also reserve the time that you would normally take to come to clinic to interact with all of our team members. If you are due for your annual evaluation from a CF team member, expect to see them virtually or talk with them on the phone. As clinical care is changing rapidly, it is especially important to make sure that all of your needs are being met.

Often the first reach out will be from our certified medical assistants (CMAs) or nurses in clinic. This may happen a few days prior to your clinic visit. They will be entering measurements and reviewing your medication lists. If you have the equipment, please check your measurements and have these numbers ready for the staff calling:

- Weight
- Heart rate and oxygen saturation
- Blood pressure
- PFTs (Home spirometry)

To participate in the virtual appointment, you will need a smartphone, tablet, or computer with video and audio. If logging into MyChart from a computer or tablet, it is best to use Chrome as your web browser.

Please log into MyChart and wait in the “waiting room” 15-30 minutes before your appointment. Care team members may see you ahead of or after your provider. Our team members may also join your providers’ video visit. We will also do our best to keep you updated of any delays.

If you have any questions or topics you would like to discuss with your provider or care team member during your appointment, feel free to reach out ahead of time through MyChart or by phone.

If you need assistance or more information on how to connect to your visit, please reference:
<https://www.unchealthcare.org/patients-families-visitors/my-unc-chart/video-visits/>



RESEARCH UPDATES

FROM MARGRET POWELL

Lots of exciting research is happening all the time, ranging from specimen collections, to observational studies and interventional studies. If anyone is interested in anything you see or hear about online, or you're curious about research, please contact your providers or the research staff (they can email me: Margret_powell@med.unc.edu, and I can forward it to the lead Research Coordinator).

Also, please check out the [Clinical Trials Finder](#), and if any studies on there sound exciting, we'd be happy to help you get involved - even if the studies are not offered at UNC!

Related to COVID, there are increased cleaning schedules, spaced out room use to minimize interpersonal contact at the research unit, HEPA filters to clean the air in the exam rooms (especially before, during, and after aerosolizing procedures), reviewed cleaning protocols (of rooms and hand-washing, etc.) with the entire staff, and heightened PPE guidelines.

CURRENTLY ENROLLING TRIALS:

Trial Name	Trial Description
<i>SPITT</i>	Currently looking for people with FEV1 > 30% who will provide induced sputum samples and are about to start Trikafta or have already started Trikafta. The study visit takes about 45 minutes and can be done after a clinic visit!
<i>PROMISE F19</i>	An MRI study recruiting people with FEV1 > 40% who have not yet started Trikafta. Study requires one visit before starting Trikafta and one about 1 month on Trikafta" visit. Each visit is about 4 hours.
<i>SIMPLIFY</i>	People on Trikafta with FEV1>60% who are either currently taking Pulmozyme or Hypertonic Saline and would be willing to trial the removal of either (or both) of these medications. Participation lasts 10 weeks, with 5 visits. 2 visits will be about 8 hours long, and the rest are about 2-4 hours.
<i>F19 LONGITUDINAL</i>	An MRI study looking at changes in lung ventilation over a year in individuals with FEV1>70%. Participation lasts 1 year with a minimum of 3 visits, with a maximum of 5 visits. Each visit lasts 4 hours. The first two visits would be when you are well; then, if you have an exacerbation, we are asking you to come in before getting treated and within 3 days of finishing treatment. The final visit is 1 year after your first visit.
<i>CALITHERA</i>	An investigational drug study looking for people with chronic pseudomonas aeruginosa with FEV1 40%-90%. It includes 6 visits (1/week) and participation lasts for 2 months. Some visits will be about 12 hours, while others are about 4-5 hours long.



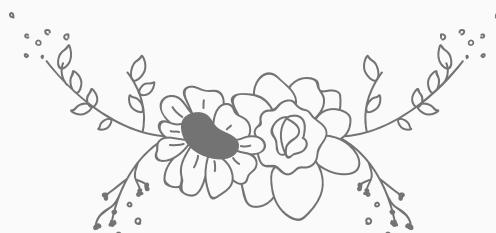
NACFC 2020 SUMMARY

From October 21-23, 2020, the UNC Adult and Pediatric CF care teams participated in the North American Cystic Fibrosis Conference (NACFC). This year looked a little bit different due to COVID-19, and instead of traveling, we attended virtually from home. NACFC is a valuable opportunity to learn from other CF Centers across the country and worldwide. It's a time to hear about the most up-to-date information and research on CF.

Each year, there are three main “plenary” sessions where renowned speakers present on the most relevant topics. This year’s topics included:

- 1) *Laying the Foundation for the Path to a Cure: The Fundamentals of Genetic-Based Therapies*
In this presentation, two CF researchers explain how we can possibly treat the basic defect in all people with CF and ultimately develop a cure. They discuss potential genetic therapies such as gene editing and gene therapy.
- 2) *Defining the New CF in the Era of Highly Effective Modulators*
In this presentation, a CF Pulmonologist talks about the latest research related to highly effective CFTR modulators, such as Trikafta, and ongoing studies.
- 3) *Advancing the GI Frontier for People with CF*
In this presentation, a CF Gastroenterologist explains the many GI aspects of CF, and the exciting research initiatives and research happening in GI as part of specialized CF care.

If you are interested in hearing more about these topics, all of the plenaries are still available on the Cystic Fibrosis Foundation Facebook page.



THE IMPORTANCE OF home spirometry

Since the start of the COVID-19 pandemic, the Cystic Fibrosis Foundation has provided home spirometers to a large number of CF patients across the country, including through our UNC Adult & Pediatric CF Centers. This effort was in response to a sharp increase in virtual care earlier this year.

You may have received a home spirometer through the CF Foundation, or you may already have a different spirometer at home. No matter what, we believe home spirometry is an extremely important tool.

So, what can home spirometry do for us? Number one, it can help us monitor lung function at regular intervals over time (i.e. your 3-month check-up). Number two, when you monitor your lung function on a more consistent basis (i.e. every few weeks), it can help you and your CF team detect CF exacerbations before you even notice any symptoms.

REMINDERS

1. Use your home spirometer at least once per month, but more often if you are able, to keep a close eye on your lung function and get used to seeing your numbers
2. If you notice a drop in your lung function, repeat a test daily for 3 days. If you notice a 10% drop in your lung function and/or have new respiratory symptoms, please reach out to your provider or nurse coordinator
3. Don't forget to use your home spirometer before any virtual visits
4. Always wait at least 30 minutes after doing your routine airway clearance (i.e. Hypertonic Saline, Vest) and/or bronchodilator treatments (i.e. Albuterol) before using the home spirometer
5. Make sure to blow out for at least 6 seconds and do 3 trials each time you do a test
6. Clean your home spirometer after each use, according to the instructions

Over the past few months, we have been creating a home spirometry program, led by two of our team members, Laura Beth Rupcich, PA-C and Donna Enloe, RT. They have been meeting with patients in person or virtually to review how to set up and use the home spirometer provided by the CF Foundation. This spirometer, called the MIR Spirobank Smart, has Bluetooth capability and works through an app on your phone or tablet. It also has the option to "share" results with your provider through an online dashboard. Alternatively, you can take a screenshot of your results and upload them to the My UNC Chart.

If you have received a home spirometer through this recent program and have not spoken with Laura Beth or Donna yet, please reach out to us to schedule a time to do so!

If you have not received a spirometer but are interested in one, please let our nurse coordinators, Nicole and Nancy, know!

STAFF UPDATES

farewell

from Marianne Buchanan

As some of you know, I've made the difficult decision to part from the Adult CF team in order to focus on the needs of my family during the pandemic. Many thanks to all of you who graciously allowed me to be a part of your journey. You've taught me more than you could possibly know. And I continue to wish you well, just from a different place.



Introducing Our Newest Staff Members



Seyram Fudzie, PharmD, CPP received her pharmacy degree from UNC-Chapel Hill in 2018. She completed her pharmacy residency training at UNC Hospitals and Clinics in June 2020. Seyram is excited to have joined the Adult CF team in July 2020 and is looking forward to meeting all of the CF patients! Outside of work, Seyram enjoys traveling, crafting, and playing with her 6 month old puppy!



Amy Nester received her Master of Social Work from Boston College in 2002 and has most recently worked as an inpatient Case Manager at UNC for the past 10 years. She is so excited to be joining the CF team in December! Outside of work, Amy enjoys spending time with her family, traveling, reading, and birdwatching.

FINAL REMINDERS

FLU SHOTS

2020 ANNUAL REMINDER

This is a reminder that it is very important for you to get your flu vaccine this season if you have not already done so. If you have received your flu vaccine locally, please call or send a message to your CF nurse so that we can update your immunization record at UNC. Thank you!

A NOTE FROM YOUR PHARMACISTS

The end of the year is upon us! Please let the team know if you are changing insurance and, if possible, upload an image of your card via MyChart. Please remember that your deductibles will reset at the beginning of the year. If you need medication assistance, please contact us!



QUESTIONS?

CONTACT YOUR CF MULTI-DISCIPLINARY TEAM

Team Member Names	Patient Last Name A-K	Patient Last Name L-Z
Nurse Navigators	Nicole Bingham 919-966-4170	Nancy Efland 919-966-7049
Dietitians	Alannah Mascarella 984-974-3357	Courtney Busby 984-974-3358
Pharmacists	Emily Wong 984-974-0012	Seyram Fudzie 984-974-1941
Social Workers	Krista Wendel 984-974-5164	
Respiratory Therapist		Donna Enloe 984-974-1418



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UNC Adult Cystic Fibrosis Center

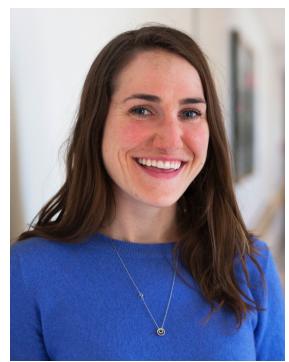
your multidisciplinary CF team



Nicole Bingham
Nurse Coordinator



Nancy Efland
Nurse Coordinator



Alannah Mascarella
Dietitian



Courtney Busby
Dietitian



Seyram Fudzie
Pharmacist



Emily Wong
Pharmacist



Amy Nester
Social Worker



Krista Wendel
Social Worker



Donna Enloe
Respiratory Therapist