

UNC ADULT CF CENTER NEWSLETTER



Happy New Year!

WELCOME MESSAGE

We've all heard the quote, "New year, New you." I recently heard a different version that I prefer – "New year, Same you, New motivations." While each of our situations and goals change over time, we're still the same at our core. I think that's a good analogy not only for our UNC Adult Cystic Fibrosis Clinic, but also for the CF community.

As we head further into 2026, one of our new motivations as the UNC Adult CF Clinic is to improve our **communication** with YOU – the patient! You could say this is one of our New Year's resolutions. We'd like to do this by creating a clinic-wide newsletter that will be shared twice a year over MyChart.

Over the past few years, our CF family at UNC has experienced a good number of changes, and we want to keep you informed. We've had staff retire and welcomed new staff to the team. One of our long-standing financial assistance partners Spiritus felt it was time to close their doors and pass the baton to another wonderful organization Filotimo, who you may already be familiar with. There have been updates with various CF-specific grants. And in addition, we are continuing to participate in new Quality Improvement and Research projects that evolve with the ever-changing face of CF.

Despite these changes, we're still the same CF Clinic – here for you with whatever you may need. We are looking forward to sharing this news with you and welcome your feedback. Enjoy!

– Laura Beth Gifford, PA-C

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SMART GOALS

FROM ALANNAH MASCARELLA, CF DIETITIAN

‘Tis the season for New Year’s resolutions! Keep the acronym **SMART** in mind as you set your goals and intentions for the year ahead. **SMART Goals** will set you up for success!

What is a **SMART Goal**?

S	M	A	R	T
<ul style="list-style-type: none">• Specific• What will you do?	<ul style="list-style-type: none">• Measureable• Is your goal quantifiable?	<ul style="list-style-type: none">• Achievable• Are you able to accomplish it?	<ul style="list-style-type: none">• Relevant• Will this improve your health/life in some way?	<ul style="list-style-type: none">• Timely• Be specific about your timeframe!

Examples:

- “Add a vegetable to every dinner meal for the next month to increase fiber intake”
- “Plan meals and snacks in advance for 2 weeks to increase nutrient density of my diet and decrease reliance on takeout”
- “Exercise for 15 minutes 3 times per week for the next 3 months”
- “Eat a protein-rich food with breakfast at least 5 days per week”



COLD & FLU SEASON

FROM NICOLE BINGHAM & ANDREA COPELAND, CF NURSE COORDINATORS

Flu cases have been increasing in the last two months. Data shows there is still good vaccine effectiveness against flu-associated hospitalizations. If you have not been vaccinated, it is **not too late to get your flu shot!** We continue to fully support vaccination for both flu and COVID and can provide these at your pulmonary clinic visit.

Besides pulmonary clinic, you can receive these important vaccines at:

- Your primary health care provider
- Pharmacy
- Health Resources & Services Administration (HRSA)-supported health centers
- Employers, schools, and community organizations
- Local health departments



COLD & FLU SEASON CONT'D

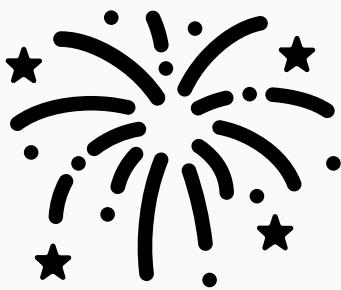
If you get your vaccines at your local pharmacy, please update your MyChart with the information.



In addition to getting vaccinated, it is important **to get tested for flu and COVID** if you develop new respiratory symptoms (runny nose, worsening cough, sore throat, fever, chills, headache, muscle aches).

- Make sure that any tests you already have at home are not expired (this can affect accuracy).
- If you test negative, but are still having concerning symptoms, test again (the following day).
- If you test positive for flu or COVID, you are eligible for antiviral medications, such as Tamiflu (for flu) or Paxlovid (for COVID). These can reduce your symptom severity, duration complication risk.
- Please contact us as soon as you test positive for flu or COVID. Antiviral medication is most effective if taken within 48 hours of the start of symptoms.
- If you are on any CFTR modulator (i.e. Kalydeco, Symdeko, Trikafta, Alyftrek), it is important to note that there are dose adjustments that need to be made to your modulator if you are prescribed Paxlovid. We will provide guidance on what to do in this case.

ANNOUNCEMENTS



In 2025, both Adult and Pediatric CF Programs at UNC were granted continued Accreditation by the Cystic Fibrosis Foundation for *excellence in care and commitment to patients!*

ANNOUNCEMENTS CONT'D

At the North American Cystic Fibrosis Conference in 2025, the UNC Adult Cystic Fibrosis Center was a recipient of the annual Cystic Fibrosis Foundation's Quality Improvement Award: *Recognizing Outstanding QI Processes and Accomplishments*



RESEARCH UPDATES

FROM SCOTT DONALDSON & JENNIFER GORALSKI, MD

Critical research designed to help people with CF live long, healthy lives is ongoing and needs your involvement! Active and upcoming studies include:

- Testing of next-generation CFTR modulators
- Genetic treatments for CF lung disease
- Approaches for better mental health in CF
- New anti-inflammatory agents
- Phage therapy for drug-resistant NTM



We encourage you to talk to your CF provider, email the CF Clinical Research Coordinator team (cfclinicalresearch@med.unc.edu), and/or check out the Clinical Trials Finder (cff.org/Trials/Finder) to learn about studies that you might be interested in learning more about. This tool lets you easily filter through the list to find certain treatment approaches, study eligibility requirements, and study locations. We would be excited to help you get involved - even if the study you're interested in is not offered at UNC!

PRIMARY CARE IN CF

FROM SCOTT DONALDSON & JENNIFER GORALSKI, MD

Historically, many people with CF used their CF provider for most of their primary care needs. This made sense because many of their health concerns were related to their CF, and it required someone with significant CF expertise to understand even minor health changes. Today, CF patients are living longer and healthier lives. As a result, health concerns unrelated to CF are increasingly important; these include cancer screening, cardiovascular health, bone health, mood disorders, and general disease prevention (vaccines, screening tests). The availability of good primary care providers and a partnership with CF experts is needed to achieve the long, healthy lives that people with CF desire and can achieve.

To support this goal, the UNC Adult CF Program is partnering with the CF Foundation and other centers. At UNC, we are developing a network of high-quality primary care providers (PCPs) who understand your specific needs and offer primary care expertise that typical CF providers usually do not have.

How are we doing this?

We asked many of you for your opinions through a confidential survey. About 50 people with CF responded. Here is what we learned:

- **About 1/3 did not have a PCP.** They used their CF specialists for most of their health concerns.
- While those who did have a PCP were happy with their overall care, **nearly half of them were not satisfied with their PCP's knowledge of CF** (and most thought this knowledge was important).
- If a PCP with basic CF training were available, opinions were split on the best location. Half wanted the PCP near their home, and half wanted them near the UNC CF Clinic.
- The majority **preferred a CF-informed PCP to manage common health problems** like obesity, high blood pressure, and high cholesterol. They also wanted them for:
 - Vaccinations
 - Minor non-respiratory illnesses
 - Routine physical exams and women's health exams (e.g., pap smears)
 - Arranging preventative health screenings (colonoscopy, diabetes screening, bone density testing)



What are we doing now?

- We have partnered with an expert primary care provider at UNC – **Dr. Karina Whelan** – who practices at UNC Internal Medicine at Panther Creek (Cary, NC - 20 min from the UNC CF Clinic). Dr. Whelan has trained with the CF team in our clinic, meets the CF team weekly as a key member of our quality improvement group, and has experience in the primary care of adults with CF. She is rapidly becoming a national leader in the primary care of people with CF!!
- Drs. Whelan, Goralski, and Donaldson have created a **CF elective** for senior UNC residents in primary care specialties (internal medicine, family medicine, internal medicine-pediatrics). During this rotation, these doctors will receive training in CF, its complications and treatments, and the role that PCPs can play in the care of people with CF. Participants will maintain a direct connection to the UNC CF Team as they move out into practice, allowing us to develop a true network of “CF-informed” primary care specialists.
- The UNC Adult CF Team are working to identify well-respected providers across the state, often within the UNC Health network of practices, to “recruit” primary care providers already in practice and offer CF training, resources, and direct team connections.
- Drs. Goralski and Whelan recently presented on the topic of primary care in CF to physicians and caregivers outside of UNC, to educate this community and develop connections between interested providers and our team.

What should you do? Talk to your CF team about your primary care needs (urgent issues, vaccinations, etc.), who you are using, and whether improvements are needed. Together, we will work with you to identify the best primary care available – whether it is locally, or closer to the UNC CF Clinic.

STAFF UPDATES

Introducing Our Newest Staff Members



Karina Whelan, MD
UNC Primary Care Physician

“I have joined the CF Team as a Primary Care Internist who is interested in caring for adults with CF. My practice is located in Cary, NC. I trained in Internal Medicine and Pediatrics but only see adult patients now. I cared for many children with CF during my training. I am an educator and teach at the medical school and have enjoyed learning about the unique preventative health needs of adults with CF and the chronic medical conditions that they face. I have 2 daughters and in my free time I enjoy cooking, reading books, boardgames, long walks outside and being silly with my family.”

STAFF UPDATES CONT'D



Jane Gross, MD
UNC Adult & Pediatric CF
Pulmonologist

"I am an Associate Professor physician-scientist who has a long-term clinical dedication to children and adults with CF. My research has focused on infection prevention and control with specific interest in nontuberculous mycobacterial (NTM) infections. I was previously an active-duty Army physician, serving for over 14 years, working in a variety of roles, in Hawaii, Colorado, and Washington state as well as deploying to the Philippines and Iraq. In my free time I enjoy hiking with my dog, stand up paddling, and travelling abroad with my two adult children."



Alex Despotes, MD
UNC Adult & Pediatric CF
Pulmonologist

"I recently completed my combined Pediatric Pulmonary and Adult Pulmonary and Critical Care fellowship at UNC and am delighted to be staying on faculty at UNC in the Pediatric and Adult CF centers. My clinical and research interests include aging related complications in CF, transitions from pediatric to adult models of care, understanding mucus clearance mechanisms as therapeutic targets, and overlaps between CF and non-CF bronchiectasis. I have a baby boy who keeps me smiling, and my hobbies include running, biking, and doing all sorts of arts and crafts."



Andrea Copeland, RN
UNC Adult CF Nurse
Coordinator

"I joined the team last year in September as one of the new CF Nurse Coordinators. I have been a nurse for 28 years and previously worked at Duke as both a CF Coordinator and a Lung Transplant Coordinator. I'm married, have 2 kids and 2 cats. I love concerts, typically attending 8-10 per year. I enjoy the mountains more than the beach, love my garden, have lived and worked in 3 states and we try to travel often throughout the year when able. I'm looking forward to getting to know you and am so excited to join the team!"

HEALTHWELL GRANT

FROM ASHLEY BUIGE & MORGAN JONES, CF PHARMACISTS

The HealthWell Treatments Grant is open again after being closed for several months. Many people use this grant to help pay for CF medicines or nebulizer supplies. A complete list of what the grant covers can be found [here](#).

This grant **does not** pay for CF vitamins or nutrition supplements. There is a separate HealthWell Vitamins and Supplements Grant, which is still closed because there is not enough funding. You may set up alerts to be notified when this grant reopens [here](#).

Some people may not need this grant if they have other help, like copay cards. This grant is very helpful for people with Medicare who may have high costs for medicines at the start of the year.

Who can renew this grant?

To renew the HealthWell Treatments Grant, you must:

- Have cystic fibrosis (CF)
- Have insurance that helps pay for medicines (like private insurance, Medicaid, or Medicare)
- Meet income limits (500% or less of the federal poverty level, based on family size) you can use this calculator [here](#) to determine if you qualify

Important Dates

- The grant lasts for one year. Everyone's end date is different based on when you enroll. You can renew your grant starting 30 days before it ends.
- You can check your grant status by logging into or creating an account on the HealthWell website [here](#).

How to renew

- If your grant has ended, you can renew it by clicking "re-enroll" in your HealthWell account. This is the fastest way.
- Sometimes HealthWell will ask the clinic to confirm your CF diagnosis. If this happens, please contact us.
- If you are having trouble or need help, you can call the clinic. Please know this is a very busy time of year, and it may take some time.
- Our clinic has already started renewing grants for many patients who need them. Even so, it is a good idea to check your own account if you think you might need this help.

If you have any questions after checking your HealthWell account, please contact the clinic. We are happy to help!



FINAL REMINDERS

CONTACT YOUR CF MULTI-DISCIPLINARY TEAM!

Disciplines	Patients with last name	
	A to K	L to Z
Nurse Coordinators	Nicole Bingham, RN (984) 974-6950	Andrea Copeland, RN (984) 974-4050
Dietitians	Alannah Mascarella, RD, LDN (984) 974-3357	Courtney Busby, RD, LDN (984) 974-3358
Pharmacists	Morgan Jones, PharmD, CPP (984) 974-6617	Ashley Buige, PharmD, CPP (984) 974-0030
Social Workers	Amy Nester, LCSW (984) 974-3385	Krista Wendel, LCSW (984) 974-5164
Respiratory Therapist	Donna Enloe, RRT (984) 974-1418	

What do I do if I am sick?

- During business hours, Monday through Friday 8:00AM to 4:30PM**, call the CF Nurse Coordinators (see above). We will discuss your symptoms communicate with your provider and then relay the plan of care.
- If after hours or on the weekends**, please call the hospital operator at **(984) 974-1000** and ask to page the Pulmonary Fellow On-Call.

