

# CF FAMILY NEWSLETTER

Fall 2025



## The Newest Modulator: Alyftrek



Last December, the FDA approved a new modulator therapy called Alyftrek (ah-LIF-trek) for individuals with CF, six years and older, with at least one responsive mutation. Much like Trikafta, Alyftrek is a combination of three drugs—vanzacaftor, tezacaftor, and deutivacaftor. Vanzacaftor is a new drug that replaces elexcaftor found in Trikafta. The other two components are similar to those in Trikafta, although deutivacaftor has been modified to last longer.

Clinical trials comparing Alyftrek to Trikafta showed that the two drugs were basically equivalent in terms of changes in lung function, exacerbations, and quality of life, though there was some evidence that people on Alyftrek have modestly better improvement in sweat chloride values. Although the new drug was primarily evaluated in people with CF who have the common F508del CFTR mutation, Alyftrek has been also been approved for individuals with many rarer mutations, including 31 that are not currently approved for use with Trikafta.

While your CF team is very excited to have a new treatment option for people with CF, we are taking a cautious approach towards adoption. Since the

clinical benefits seem very similar between Trikafta and Alyftrek, we have generally suggested that those doing well on Trikafta continue with that medication.

One advantage of Alyftrek is that it only has to be taken once daily, although your team has found that once daily dosing of Trikafta can also be effective and is an option we can offer to those interested. We have some concerns that components of Alyftrek are much slower to be removed from the system, which could be an issue for anyone who develops side effects. People interested in Alyftrek should also be aware that current guidelines recommended significantly more bloodwork for patients starting a new modulator, including switching from Trikafta to Alyftrek (monthly for six months and then quarterly for a year).

As always, your CF team is happy to have discussions about whether Alyftrek is a good choice for you or your loved one with CF. Alyftrek does have an important role for those who did not tolerate Trikafta or who have mutations that are only approved for the newer drug. We will also continue to monitor the situation to see if newer evidence would change our recommendation.

# CF Nutrition: Feeding the Picky Eater

Mealtime battles can be a real struggle. Even with these tips it may take time, patience and consistency for your child to try new foods. If you have any questions or concerns about your child's picky eating, you can reach out to your cystic fibrosis dietitians.



## Get them involved:

Try exposing them to refused foods in other ways such as reading books about different foods, growing a garden, preparing meals together, have them grocery shop with you.

## Create positive environment:

Ignore refusal of foods and carry on with your meal.

## Mealtime routines:

Set mealtime routines where you can enjoy eating and being social together.

## Celebrate small wins:

Praise your child when they do something positive during mealtime. Try giving them an instant positive reinforcement like a high-five, hug or small reward.



## Try, try again:

Be patient and keep trying new foods. It can take up to 8-15 times for your child to accept a new food. Introduce a new food with something they enjoy.

## Make it fun:

Offer food in different shapes using cookie cutters. Use fun themed utensils and plates at mealtimes.



# QI Corner

The Pediatric CF Team is continuously working to improve the care that we provide to our patients and their families. We use quality improvement methods and science to help us do so. Current projects that we have been working on include:

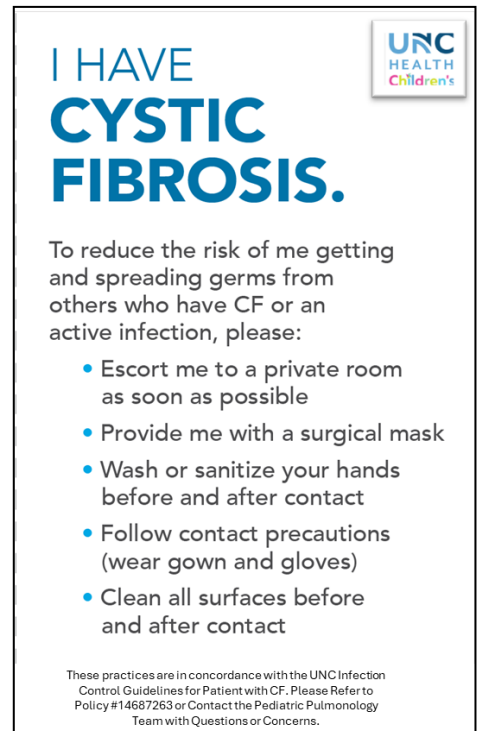
## CF Passport

Regular visits to our CF clinic are an essential part of maintaining your child's health. While in clinic or other areas of the hospital, we follow strict infection control guidelines from the Cystic Fibrosis Foundation to help prevent the spread of germs between patients with CF and others.

To further support these efforts, we're introducing a new tool designed by the CF Foundation called the CF Passport—a simple, effective way to help ensure that all hospital staff are aware of and following appropriate precautions for individuals with CF.

The CF Passport is a small card that patients and families can carry and present to staff in areas of the hospital that may not be as familiar with CF-specific infection control practices. While UNC Health's policies already incorporate these guidelines, the passport serves as a helpful reminder and advocacy tool for families.

We'll have CF Passports available in clinic—just ask your next visit. You should also receive a printable copy via email or MyChart if you'd like to keep a copy on hand. If you have any questions or feedback, please don't hesitate to reach out. We're grateful for your partnership in keeping our CF community safe.



**I HAVE  
CYSTIC  
FIBROSIS.**

To reduce the risk of me getting and spreading germs from others who have CF or an active infection, please:

- Escort me to a private room as soon as possible
- Provide me with a surgical mask
- Wash or sanitize your hands before and after contact
- Follow contact precautions (wear gown and gloves)
- Clean all surfaces before and after contact

These practices are in concordance with the UNC Infection Control Guidelines for Patient with CF. Please Refer to Policy #14687263 or Contact the Pediatric Pulmonology Team with Questions or Concerns.

# UNC Patient Family Advisory Board

Being part of the Family Advisory Board at UNC has been an incredibly meaningful experience for me. As a parent of two daughters with CF, I've had the privilege of serving on the board on and off over the years. This role has allowed me to work closely with the hospital team to help improve patient care while ensuring that the family and patient voice is represented. It's truly rewarding to see how collaboration between families and hospital administration can strengthen the overall care experience.

The Family Advisory Board serves many important purposes beyond providing feedback—it helps guide programs, enhance communication to families, and provides a supportive community for patients and their families. I encourage everyone to consider getting involved and sharing their perspectives. Together, we can continue making the UNC CF Center the very best it can be for everyone impacted by cystic fibrosis. To learn more or express interest in joining, please reach out to your CF Center team.



# Recent and Upcoming Policy Changes Affecting Insurance and Access to Care

There is currently significant activity at both the state and federal level that could impact access to care and insurance coverage for people with cystic fibrosis (CF) and their families.

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## State-Level: North Carolina Medicaid

- **Budget Shortfall:** North Carolina Medicaid is underfunded by approximately \$319 million for FY26. With no state budget passed, the program began implementing service reductions and rate cuts (3–10%) on October 1, 2025 to remain within budget, as required by law.
- **Impact on Access:** Cuts of this size may force providers—especially independent practices in rural communities—to limit services for Medicaid beneficiaries. Patients may face longer wait times and difficulty scheduling appointments.
- **Next Steps:** If the General Assembly appropriates additional funding in October, these impacts could be minimized.

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## Federal-Level: Health Insurance Marketplace

- **Government Shutdown:** As of October 1, 2025, the federal government entered a shutdown due to the inability of Congress to pass a new budget.
- **Premium Tax Credits:** A major point of conflict is the elimination of premium tax credits (subsidies that help individuals and families afford insurance purchased through the Affordable Care Act Marketplace). These were cut in the “One Big Beautiful Bill” passed in July 2025.
- **Impact on Costs:** Without these credits, beginning November 1, 2025, premiums could rise 9–30% annually for up to 1 million North Carolinians. As plans become unaffordable, more individuals may lose insurance, increasing the number of uninsured in the state.

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## Other Policy Changes Affecting CF Patients

- **COVID-Era Expirations:**
  - ⇒ The low-income open enrollment option ended August 25, 2025.
  - ⇒ Enhanced premium tax credits will expire at the end of 2025,

further raising costs.

- **Open Enrollment and Documentation:**
  - ⇒ Starting January 1, 2026, open enrollment periods will be shorter (ending December 31).
  - ⇒ Applicants will face increased documentation requirements (e.g., proof of income).
- **Medicaid Work Requirements:**
  - ⇒ Non-disabled adults may be required to complete 80 hours per month of work, school, or volunteering to maintain coverage.
  - ⇒ Implementation timelines are still pending.
- **Retroactive Coverage and Cost-Sharing:**
  - ⇒ Medicaid retroactive coverage will be reduced.
  - ⇒ Some beneficiaries may face new co-pays for certain services.

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## Support for Patients and Families

- **Compass** is a team of CF patient advocates who assist with financial, legal, and insurance-related issues for people with CF, their families, and providers across the U.S.
  - ⇒ **Free and confidential:** No insurance, income, or citizenship status required.
  - ⇒ **Bilingual support:** Spanish-speaking case managers are available.
  - ⇒ **Personalized process:** Intake includes gathering detailed patient information, assigning cases to specialized managers, conducting research, providing plan comparisons (typically three options), and supporting families through decision-making, transitions, and prior authorizations.
- **Additional CFF.org Resources:**
  - ⇒ **Educational resources:** Explore the Navigating CF video series on insurance and financial topics.
  - ⇒ **Advocacy alerts:** Sign up to receive timely updates on state and federal policy changes that may affect CF patients.

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## Key Takeaways

Policy changes at both the state and federal level are evolving quickly. Families should:

- Stay informed through their CF care team and Compass.
- Plan ahead for shorter enrollment timelines and potential cost increases.
- Use Compass and CFF resources for personalized support in navigating coverage and financial challenges.

# Food Insecurity at UNC Pediatric Cystic Fibrosis Center



## What is Food Security?

- Food security means having reliable access to enough affordable, nutritious food to stay healthy and active.

⇒ Over **47 million people** live in food-insecure households in the U.S.

⇒ In NC, **1 in 6 children** face food insecurity

## Why Food Insecurity Matters

- People experiencing food insecurity are at greater risk for:

⇒ Poor health and higher health care costs

⇒ Developmental or behavioral challenges in children

- **Signs you may be experiencing food insecurity:**

⇒ Not having enough food at home or worrying about running out

⇒ Buying lower-quality or less varied food

⇒ Eating smaller amounts or skipping meals

⇒ Living in areas with limited affordable food options

## Food Insecurity and Cystic Fibrosis (CF)

- People with CF may face food insecurity at higher rates due to:

⇒ High cost of CF care and treatment

⇒ Needing nearly **double the calories** compared to those without CF

⇒ Limited public programs that do not fully meet CF nutritional needs

⇒ Barriers to private food programs (location, hours, availability of CF-appropriate foods)

## Why Talk to Your CF Care Team?

- Living with CF is expensive, and stretching food budgets can sometimes affect health. Examples:

⇒ Cutting back on high-calorie, high-protein meals or shakes

⇒ Choosing between food and rent/utilities

⇒ Skipping meals so your child with CF can eat

⇒ Adjusting or skipping medication altogether

⇒ Choosing between groceries and gas to get to clinic

⇒ Your CF team asks every patient at every visit about food security — not to judge, but to connect you with help. Food insecurity can happen to anyone at any time.

## How Can I Get Help?

- Nearly two-thirds of individuals with CF experience financial hardships including food insecurity, yet many hesitate to ask for help. Please know:

⇒ Food insecurity affects many people for many reasons

⇒ It is **not your fault**

⇒ Your CF team is here to partner with you

⇒ Complete your CF Visit Questionnaire and Food Insecurity Screening

⇒ Ask to speak to your **CF social worker** for immediate access to CF optimal food today

**Food insecurity is more than a food problem — it is a health problem. Together, we can make sure that your child has the nutrition needed to stay as healthy as possible.**

# Help Welcome Our New Fellows!

Meet our newest Pediatric Pulmonology Fellows.

## Daniel Vo, MD



**Where are you from?** Seneca, SC

**Where did you go to university, med school, residency, etc.?** I went to University of South Carolina for both undergraduate studies and medical school. I did my residency training at Phoenix Children's.

**Any past jobs or interesting facts about your career thus far?** I knew I wanted to do pediatrics since day 1 of medical school!

**What are your passions/scholarship focus while in Fellowship?** Environmental impacts on respiratory diseases, asthma, interstitial lung disease

**What is one interesting personal fact about yourself?** I can play 3 instruments: piano, cello, and the harmonica.

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## Kaitlin Tillman, MD



**Where are you from?** Memphis, TN

**Where did you go to school?** I went to undergrad at Baylor University in Waco, TX (majored in biochemistry with a minor in Spanish), medical school at University of Tennessee Health Science Center (UTHSC) in Memphis, TN and residency at UTHSC/Le Bonheur Children's Hospital in Memphis, TN.

**Any past jobs or interesting facts about your career thus far?** Honestly, not much that's too exciting at this point since I've been in medical school/residency for the past 7 years! I did work at a summer camp and spent 2 years as a supplemental instructor in organic chemistry when I was in college.

**Why did you choose Pediatric Pulmonology?** My experiences with patients with CF and their families played a large part in my decision to go into pediatric pulmonology. From a medical perspective, CF is an interesting condition with regards to its impact on several body systems. As part of the CF care team, we are able to develop a special relationship with our CF patients and families as we follow them from birth onward! The advances in CF care with new modulators is also very exciting, and I'm particularly interested in how these new therapies alter CF care moving forward.

**What do you like to do in your free time?** I enjoy running and have done several half marathons. I also like to hike and cook!

# Protecting Our CF Community

## This Flu Season



Dear CF Families,

As we enter another flu season, your CF care team at UNC and The Cystic Fibrosis Foundation want to remind you of the importance of flu vaccination for individuals with cystic fibrosis and their loved ones.

People with CF are at increased risk for complications from respiratory viruses like influenza. The flu can lead to exacerbations, hospitalizations, and long-term impacts on lung health. That's why we strongly recommend that everyone in your household receive a flu vaccine this season.

Flu vaccines are available in our clinic. If your child receives their vaccine elsewhere—such as at a pediatrician's office, health department, or pharmacy—please let us know the date so we can update their UNC medical record and the CF Foundation Patient Registry (if applicable).

For more information from the Cystic Fibrosis Foundation about how flu affects people with CF, you can visit this website <https://www.cff.org/managing-cf/influenza-flu>. We've also included Frequently Asked Questions and answers about the flu vaccine below.

If you have any questions or concerns, don't hesitate to reach out. We're here to support you and your family in staying healthy this season.

### Flu Vaccine FAQs for CF Families

1. Why is the flu vaccine especially important for people with CF?  
People with CF are more vulnerable to respiratory infections. The flu can worsen lung function and lead to serious complications like pneumonia or hospitalization. Vaccination helps reduce these risks.
2. Who should get the flu vaccine?  
Everyone aged 6 months and older should get a flu vaccine annually, unless they have a specific contraindication. This includes all family members and caregivers of people with CF.
3. Can the flu vaccine cause the flu?  
No. The flu vaccine does not cause flu. It contains inactivated or weakened virus components that help your body build immunity without causing illness.
4. Are flu vaccines safe for children with CF?  
Yes. Flu vaccines are safe and recommended for children with CF. Side effects are generally mild, such as soreness at the injection site or low-grade fever.
5. Can my child get the flu vaccine with other vaccines?  
Yes. Flu vaccines can be given at the same time as other routine vaccinations.
6. How long does it take for the flu vaccine to work?  
It takes about two weeks after vaccination for the body to develop protective antibodies.
7. What if my child has an egg allergy?  
Most flu vaccines are safe for people with egg allergies. There are also egg-free options available.
8. When is the best time to get vaccinated?  
September and October are ideal. However, vaccination is beneficial as long as flu viruses are circulating, which is usually through the end of Spring season.

# RESEARCH



**REACH: An observational study for people with CF who do not take CFTR modulators**, ages 12+. Researchers will use the health information collected from this study to improve medical understanding of CF and to advance new therapies for people with CF. There is an accompanying website with more information at [reachcfstudy.com](http://reachcfstudy.com).

**STOP-PEDS: Study to evaluate two antibiotic treatment approaches for the management of outpatient pulmonary exacerbations in children 3 to 18 years old**, Ages 3-18; The STOP Peds study will evaluate the safety and effectiveness of two antibiotic treatment approaches for pulmonary exacerbations in children with CF. Those in the immediate antibiotics treatment arm will be prescribed 14 days of oral antibiotics. Those in the tailored therapy treatment arm will only begin antibiotics if they meet certain criteria, such as their symptoms worsen or do not improve over time.

**SUN-CF: Screening for Unmet Needs in Cystic Fibrosis**; Reach out to Caroline Flowers for more information.

**F19 K23: 19F MRI in Healthy Children and Children With Mild Cystic Fibrosis Lung Disease** ([clinicaltrials.gov NCT06066723](http://clinicaltrials.gov/NCT06066723)), Ages 6-17; Children and adolescents (6-17 years old) with cystic fibrosis (CF) who have normal spirometry will undergo 19F MRI with the inhalation of an inert contrast gas to study ventilation. Comparisons will be made to a cohort of healthy children (6-17 years old) who will perform the same measures. The primary outcome measure is the feasibility of conducting these studies in the pediatric population.

**Mental Health Risk and Resilience in Caregivers of Children with Cystic Fibrosis**, legal guardian and caregiver of a child with CF (between 2-12 years of age), This study involves completing a 30-45 minute questionnaire on a secure website and allowing access to your child's medical record to collect de-identified medical information. Participants will receive a \$40 electronic gift card. If you would like to learn more, please contact Kelly Moormann at [kelly.moormann@med.unc.edu](mailto:kelly.moormann@med.unc.edu).

**Sinus Disease in Young Children with CF**, "Do you have a child with cystic fibrosis under 11 years old? We invite you and your child to participate in a research study led by Dr. Jane Gross to help understand how CF affects the sinus and sense of smell. Participants will complete a quick sinus MRI scan and some surveys once a year for 5 years. Each visit will be compensated for \$50 and reimbursed for travel costs. Contact Mia Sharrock ([mia.sharrock@unc.edu](mailto:mia.sharrock@unc.edu) / 919-445-4788) for more details."

**TIDES 2.0**, a national study aimed at understanding the well-being of children with CF. Children 2-11 years of age will be strategically enrolled so investigators can learn more about depression, anxiety, and behavior problems in children with CF and how these issues change over time. Investigators will also study side effects related to CF medications.

## **CF Nontuberculous Mycobacteria (NTM) Research**

Nontuberculous mycobacteria (NTM) are bacteria that live in soil and water and can cause chronic pulmonary infection in people with cystic fibrosis (CF). These infections may lead to severe lung disease and are often very difficult to treat. The most common infections are caused by *Mycobacterium abscessus* complex and *Mycobacterium avium* complex. People are exposed to NTM infections on a regular basis, but only a small percentage of people will develop NTM lung disease. Dr. Gross's lab is interested in understanding the sources and pathways of how NTM infect people with CF. She is the principal investigator of the Prospective Healthcare-Associated Links in Transmission of NTM (HALT NTM) Study to identify and mitigate potential NTM infection outbreaks at CF Care Centers. Specifically, this study identifies NTM respiratory isolates collected from people with CF and compares the respiratory isolates to each other as well as NTM isolates recovered from dust and water biofilms in the healthcare environment. This study will help us better understand the mechanisms that cause NTM infections in people with CF.

## **CF *Mycobacterium abscessus* Research**

Dr Gross is the site PI for a study called POSTSTAMP, A Prospective Standardized Assessment of People With Cystic Fibrosis and Non-tuberculosis Mycobacteria Pulmonary Disease Undergoing Treatment With Mycobacteriophage. About 10 people with cystic fibrosis (CF) and persistent Nontuberculosis mycobacteria (NTM) infection despite treatment will be screened to find out if their NTM infection has at least one mycobacteriophage that is effective in killing the mycobacteria. Individuals who are found to have at least one phage will be offered assistance in pursuing FDA approval for treatment via expanded-access Individual New Drug (IND) for compassionate-use. They will receive phage treatment for 1 year along with their guideline-based antibiotics for NTM. Individuals who are not identified as having a phage match will be followed as they continue to receive guideline based antibiotic therapy for 1 year. All subjects, including those who do not have a phage match will continue to be observed for the duration of the study, or about 1 year.

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If you'd like to learn more about research in general or may be interested in discussing any of these research studies, please reach out to Caroline directly at [caroline\\_flowers@med.unc.edu](mailto:caroline_flowers@med.unc.edu) or 984-974-2962.



## Join in on CF Parent Education Nights!

Don't miss an opportunity to join upcoming virtual workshops to help you navigate life as a parent of a child with Cystic Fibrosis! You can find out more, watch previous workshops, and sign up here:

[www.cfparenteducation.com](http://www.cfparenteducation.com)

I am excited to be  
**attending NACFC 2025.**  
I can't wait to see and  
connect with everyone.

**REGISTRATION IS NOW OPEN**

**nacfc2025**  
**SEATTLE**  
OCTOBER 22-25, 2025

\* Free Virtual Registration is open if you would like to attend some session live. Sessions are also available on the CFF YouTube a couple weeks following the event.

\* NACFC 2025 Merch is also available for purchase!

## Help Us Make the Newsletter Better!



If you would like to submit an article or have an idea for the next CF Family Newsletter, please contact Kelly Moormann at [kelly.moormann@unc.edu](mailto:kelly.moormann@unc.edu).

## Contact Us

**Scheduling:** 984-974-7337  
(En Español: 919-966-6669)

**Pulmonary Office:**  
919-966-1055 (8am-4:30pm)

**CF Nurses:**  
919-966-1055 (9am-4pm)

**Hospital Operator:**  
984-974-1000

**Visit us on the web at:**  
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