INSPIRE SPRING 2025

URMC CF Program

CF Fighter Care Packages

Are you a CF Fighter? Claim your care package now! CF Fighter care packages include a new CF Fighter t-shirt, CFF branded goodies and CFF support program information. Click on this link https://afasignup.formstack.com/forms/2025_cf_fighter_shirt_order_form or email western-newyork@cff.org to request yours, compliments of the CF Foundation's Western New York Chapter.

'Our Pediatric Cystic Fibrosis (CF) center is excited to start a new research study in 2025. As you know, CF causes periods of new or increased cough and other respiratory symptoms called pulmonary exacerbations. Exacerbations are often treated with antibiotics and increased airway clearance. In milder pulmonary exacerbations (respiratory illnesses) that are managed at home, we don't know if antibiotics are always necessary. In this study, we are going to compare two ways of treating mild respiratory illnesses in children with CF: immediate antibiotics (increase airway clearance and start oral antibiotics right away) or tailored therapy (increase airway clearance right away but only start oral antibiotics if symptoms worsen or do not improve). We are looking at how safe each option is and how well each one works. To do this, we will randomize you (like flipping a coin) to one of these two approaches if or when you have a mild respiratory illness over the next 12 months. We would appreciate if you would consider participating. Please speak with your CF care provider or email Barb Johnson (barbara_johnson@urmc.rochester.edu) if you have questions or are interested in participating.'

We have good news! The New York State Adult Cystic Fibrosis Program is open and accepting applications from eligible persons with CF.
Contact us directly at (855) 226-2295,
Monday thru Friday from 9:00 am to 5:00 pm ET to apply.

To qualify you must:
Be a legal New York State resident for the last twelve consecutive months
Be 21 years of age or older
Have a diagnosis of Cystic Fibrosis that you are actively being treated
Have some form of primary private health insurance or Medicare and not eligible for state Medicaid.

Sign in to your patient portal directly to submit your verification documentation and submit claims by visiting: https://hwfdirect.my.salesforce-sites.com/patients?organization=nystate . Your provider can request portal access by emailing portal@hwfdirect.org.

If your current grant has ended you still have time to submit claims for consideration. For reimbursement please submit:
A completed Reimbursement Request Form
Proof of amount paid by insurance
Proof of payment paid by patient directly
Documentation must include the patient's name, date of service, product or premium amount, and patient's responsibility

Please note, claims are paid based on available funding at the time of submission and there is no guarantee of reimbursement.

New York State Adult Cystic Fibrosis Program

What is the ACFAP and what does it cover?
The ACFAP is a state-sponsored program, administered by Health Well Fund Direct LLC, that provides financial assistance for CF-related medical care and/or insurance premiums to eligible New Yorkers aged 21 and older who are not eligible for Medicaid.
The ACFAP reopened in March 2024 after being closed for four years and is currently accepting applications and claims for medical expenses. To apply, contact HWF Direct Monday - Friday, 9:00 a.m. - 5:00 p.m. EST at 1-855-226-2295.
The ACFAP provides financial assistance for:
➢
Insurance premiums from January 1, 2023, and onward
➢
All other eligible services, including prescription copays and medical services, used from January 1, 2022, and moving forward
How do I confirm my enrollment and get reimbursed?
If you already started your application, make sure you've completed your enrollment by calling 1-855-226-2295 anytime between Monday - Friday, 9:00 a.m. - 5:00 p.m. ET. After your initial phone call, you will receive an email inviting you to complete the verification process in partnership with your CF care center through the online portal. You will need to submit a form verifying your CF diagnosis and residency.
Login to the portal to stay updated on the status of your application. Once enrolled, you may submit all claims through the online portal. Depending on the type of service, you may be asked to provide receipts from your pharmacy, bank statements, or bills from your insurance company.
For additional assistance, reach out to CF Foundation Compass by calling 844-COMPASS (1-844-266-7277) or emailing compass@cff.org.
What can I do to ensure the ACFAP continues?
The CF Foundation continues to advocate to ensure the success of this vital program. Scan the QR code to sign up to receive more information about our efforts.

I am Diana Johnson the Social Worker at the Complex Care Center an in my role, I also provide Patient Navigation Services and Care Management. I joined the Complex Care Center in July 2023. In July 2024, I started completing the annual biopsychosocial assessments with all our CF and Sickle Cell patients. During this assessment we will review your current mental and social health status. So, if we have not met yet, we will soon, and I look forward to meeting you.

In my role I also review your mental health screening scores (PHQ, GAD) with you. It is important to have accessible mental health resources, and support so at the time I will provide any needed and/or requested resources. Ensuring our patients have the right tools and supports can make the difference in your mental well-being and that is my goal.

Hello, my name is Angela Burns, and I am excited to be joining the CCC team. I have had the pleasure of working with URMC for over 13 years. My most recent position was in Physical Medicine and Rehabilitation, and before that, I worked at Interlakes Oncology Hematology. I have truly enjoyed my training so far, and it has been an amazing experience. I look forward to meeting each of you in passing and contributing to our collective success.

Life with CF can be incredibly challenging for the person living with CF and their loved ones. CF Foundation has heard a need for a community that understands and can listen with real world experience. We all know that your care center tries it's best to take excellent care of you but it's not the same as the understanding of someone who has walked a similar path. The CF Foundation has a program called PEER CONNECT that help people connect with others in similar situations for support. They have options for one-on-one conversations or small group discussions. Reach out if you would like to connect.
https://www.cff.org/support#peer-connections

The annual Kit Taylor Memorial Lectureship, established in the memory of Kathryn Irene Taylor, will be held on April 23, 2025. Our visiting lecturer this year will be Dr. Michael Narkewicz. Dr. Narkewicz is nationally recognized for his expertise in pediatric hepatology and liver transplantation and cystic fibrosis liver disease. Dr. Narkewicz has been an important leader in advancing GI care for people with CF and has been pivotal in providing mentorship for other CF care center providers around the world.

We would like to invite community members to attend an informal gathering on April 22nd at 6 pm that will include the opportunity to hear from Dr. Narkewicz regarding advances in CF care and his vision for the future, food will be served. Please reach out to Alexandra Johnson (Alexandra_johnson@urmc.rochester.edu) for more details if you are interested in attending this event.

Dr. Narkewicz will also present Pediatric Grand Rounds on April 23rd at 8 am.

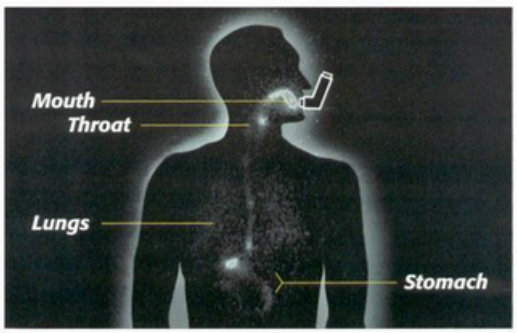
The CF Foundation is there for the CF Community in so many ways. One of the most valuable ways they can help is with Compass. If you have questions or concerns, please reach out to them. They have so many resources at their disposal. Below is the description from the CFF website:

CF Foundation Compass is a service that helps people with CF and their families with navigating insurance options, connecting to legal information and experts, finding available financial resources, and tackling other life issues.

Insurance coverage and benefits
Resources to pay for therapies and medications
Legal information on disability and government benefits
Legal information on employment or school issues
Dealing with other concerns related to life with CF
Email to compass@cff.org
Contact at 844-COMPASS (844-266-7277)

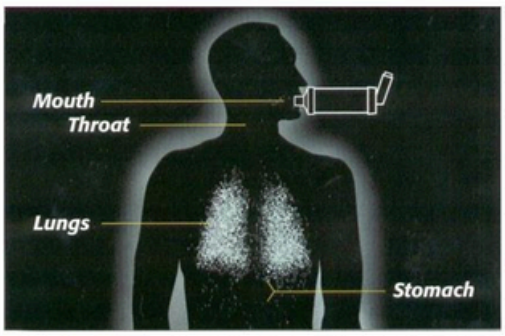
It has been my experience as an RT for 40 years that many people (providers and patients) feel that at a certain point, your technique with an inhaler is good enough that you no longer need to use the spacer with the inhaler. This graphic shows the difference in how much medication is delivered to the lungs with and without a spacer. My recommendation is to ALWAYS use a spacer with your inhaler medications (unless advised by your provider) to get the most benefit from your prescribed medication.

Why use a Spacer with an Inhaler?



Inhaler alone

When an inhaler is used alone, medicine ends up in the mouth, throat, stomach and lungs.



Inhaler used with spacer device

When an inhaler is used with a spacer device, more medicine is delivered to the lungs.

"Comparative respiratory deposition of ^{99m}Tc labeled particles of albuterol using a metered dose inhaler, a metered does inhaler with Aerochamber® spacer and OptiChamber® spacer in healthy human volunteers using gamma-scintigraphy," R. Beihn, PhD, Scintiprox, Inc., Indianapolis, IN and D. Doherty, MD. Dept. of Pulmonology, University of Kentucky Medical Center, Lexington, KY, 1997.

Images kindly provided by Respironics HealthScan Inc.

Allies Against Asthma, Center for Pediatric Research, 855 W. Brambleton Ave., Norfolk, VA 23510, 757-668-6435

Looking to get involved!?

Our local CF community has an amazing network of folks who are connected by their relationship to CF or to someone who has CF. Below are a couple of places to start!

Cystic Fibrosis Foundation - Western NY Chapter
Great Strides – local annual community event (outside 😉) to gather & support the CFF mission
Grampions – For Grand Persons of people with CF – even if you aren't a direct caregiver – Join this growing community to find connection, support, and volunteer opportunities.

Tomorrows Leaders - Young professionals – networking
Advocacy – lots of ways to get involved

Patricia (Patty) Schwarzweller
CFF Western New York Chapter
Associate Executive Director
Cystic Fibrosis Foundation | WNY Chapter | Rochester, NY
O: 716.204.2535 | M: 585.924.0319
Email: pschwarzweller@cff.org

Cystic Fibrosis Family Connection

CFFC is a charitable, not-for-profit corporation established to assist cystic fibrosis patients and their families.
CFFC was founded as an umbrella for a variety of activities to help CF patients and their families cope with the challenges of this disease. For more information or to get involved, check out: https://cffamilyconnection.org
Or email: info@cffamilyconnection.org

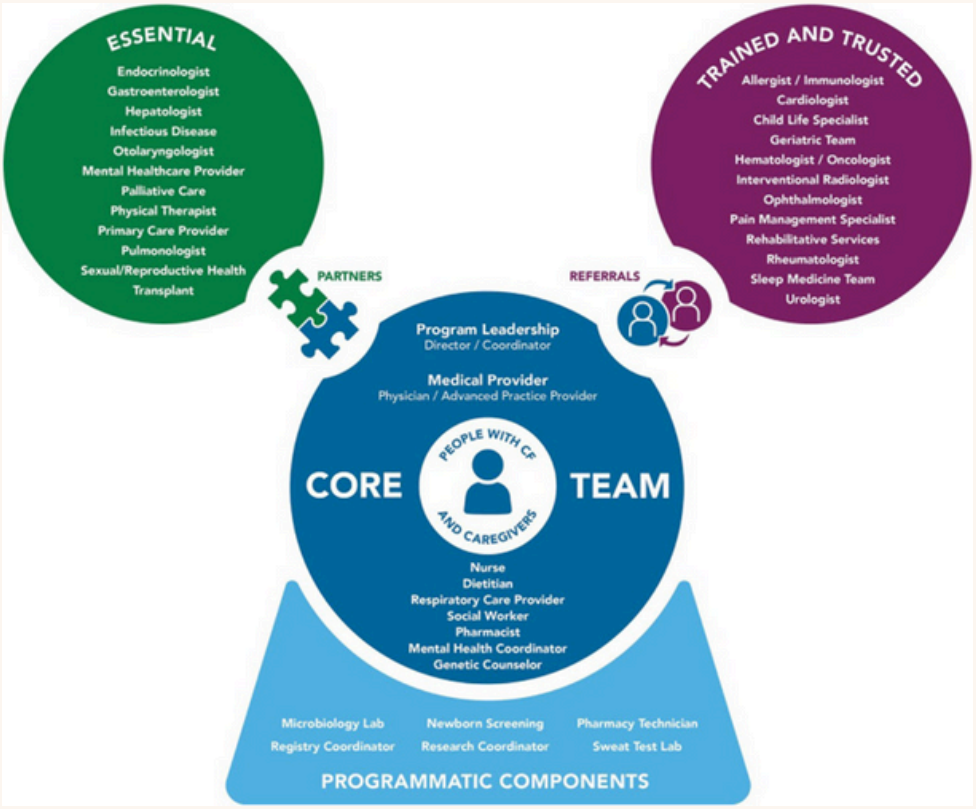
For additional supports or ways to get involved, contact:
Marcy Odell, LMSW
Pediatric Cystic Fibrosis Center

32 Strawberry Hill Court, Suite 11
Stamford, CT 06902 USA
(203) 276-5949

Dear Friends and supporters,
Many of you have donated your Trikafta and you've made a life changing difference in the lives of our patient population. I'm hoping this letter will inspire you to remember the patients who are so in need when the transition from one modulator to another occurs, by contacting and sending me any left over doses of Trikafta. We are also always in need of enzymes, Albuterol, HS 7% and Pulmozyme.
We hope you'll continue to spread the word where able and encourage all cf patients in your practice, friends and PFAC groups associated with your care team to donate to https://www.cfbridgeofhope.org/

* If the cost of shipping is a financial burden we can send a FedEx label. Please email us at cfbridgeofhope@gmail.com

At CF Bridge of Hope our mission is to improve the health of individuals with cystic fibrosis, and extend the same treatments that are available in the United States to those who live in resource-limited areas of the world.
Sincerely, Bean Corcoran
203-858-2149
Shipments:
Dr Raissi
32 Strawberry Hill Ct.
Suite 11
Stamford Ct 06902



What's all this talk about the CF care model?

At NACFC last year there was a lot of talk about new care guidelines. Specifically, who should be on the CF care team and do we still need to see everyone every 3 months? Did you know that the CF foundation has published these new guidelines about these very two topics? Obviously with the significant improvement in their health that many patients are experiencing since starting Trikafta many patients are feeling so well they don't won't to come and see us as often as they used too. So, the CF foundation has heard this and put together experts (including patients and family members) to provide some guidance.

What about team structure? The major changes to team structure in the new guidelines are:

"Continued emphasis on having "core" team members. This includes program leaders, CF medical providers, respiratory therapist, dietician, clinical pharmacist, social worker, mental health coordinator, nurses with CF experience, and a genetic counselor."

The good news is that our center already meets these guidelines.

Here's the link to the "team structure" guidelines:

Cystic fibrosis foundation position paper: Redefining the cystic fibrosis care team - Journal of Cystic Fibrosis

But what about how often patients should be seen?

The major changes to visit frequency in the new guidelines are:

"Reduced CF clinic visit frequency in children ≥ 6 years and adults to every 4–6 months can be considered when health is determined to be stable in all domains, including physical, mental and social determinants of health."

Let's tackle what these words above actually mean:

· First, these are guidelines – they are not rules. Every center needs to carefully consider if and how to put them in place. They don't replace judgement of providers and they don't replace conversations and shared decision-making with you

· "When health is determined to be stable." They don't apply when someone's health is fluctuating between visits, when lung function is dropping or when there are other conditions present that need closer monitoring (diabetes, weight loss, liver disease, mental health concerns)

What do these new visit frequency guidelines mean for our programs/center?

Both programs are discussing what we think about these guidelines and how we might follow them so more to come on that.

In the adult program our team has already begun to put together a flowsheet that allows us to think and talk with you about how to apply these guidelines to your care. Be sure to talk with your provider at an upcoming visit about how these guidelines might apply to you.

Here is the link to the visit frequency guidelines:

Cystic fibrosis foundation position paper: Redefining the CF care model - Journal of Cystic Fibrosis

The FDA approved the once daily triple combination modulator Alyftrek on 12/20/24 for people with CF ages six and older who have at least one F508del mutation or one of 31 rare mutations not previously approved for a modulator. Alyftrek consists of vanzacaftor/tezacaftor/deutivacaftor.

In clinical trials Alyftrek showed results that were comparable to Trikafta in improving lung function and Alyftrek did a better job of sweat chloride level reduction compared to Trikafta. It is unknown at this time if insurers will alter their coverage of Trikafta in response to Alyftrek's approval, but there will likely be variances amongst providers. Expect several months for insurers to review the drug and decide how to cover which, will also impact when this modulator may be available to you. Monthly liver function tests will need to be obtained for the first 6 months of treatment with Alyftrek. After six months the monitoring gets spaced out to every 3 months for the next year. After 18 months of treatment, liver function test monitoring can be done yearly.

A complete list of mutations that are eligible is available in clinic or on the VERTEX website https://www.vertextreatments.com/