

# Spring Newsletter

University of Rochester Cystic Fibrosis Center 2024

## Upcoming Events

Great Strides—  
Sunday, May 19th

Swinging fore a cure—  
Monday, August 14th

CFFC Education Day—TBD

## Check this out!



[CF Foundation YouTube Channel](#)

## Do you have unused medication?

At CF Bridge of Hope our mission is to improve the health of individuals with CF and extend the same treatments that are available in the U.S. to those who live in resource-limited areas of the world. We provide medications for a year to our patients who travel at our expense to the U.S. for care with Dr. Hossein Sadeghi and Dr. Golnar Raissi, CF Bridge of Hope Founders. We are completely free of charge.

We need your help!

Please send any unused, unopened, unexpired medications including enzymes, MVW, Pulmozyme, and modulators for us to distribute to our patients. “

Email: [cfbridgeofhope@gmail.com](mailto:cfbridgeofhope@gmail.com) and we will send you a FedEx label.

Ship to: Dr. Golnar Raissi  
32 Strawberry Hill Ct  
Suite 11  
Stamford CT 06902



Hi, my name is Heather Fico I have worked at the University of Rochester for 16 years. I started at the Complex Care Center in 2022 as a physician support specialist and after about 10 months got promoted to the Office Manager. It has been an honor for me to join the team here at the Complex Care Center and truly enjoy coming to work. In my spare time I enjoy camping, and spending time with my family and friends.



## New Faces at the Complex Care Center



Alyssa Jacek, NP joins the Complex Care Center after 3 years in Movement Disorders Neurology. She is very excited to learn more about CF and provide comprehensive patient centered care within UR Medicine the CF Center



Hello, I am Alison Diehl and I am the Research & Grants Administrator for the Division of Transitional Care Medicine. The Adult Cystic Fibrosis Care Center is housed at the Complex Care Center which is part of this division. As the grants administrator I am involved in all aspects of grants within our division including all our Cystic Fibrosis Foundation grants.

I review any opportunities for new grants, assist with grant submissions, and prepare the budgets. I work very closely with the Principal Investigators to compile and submit all of the grant reports and expenditure reports. I will follow the grant from the developmental stage until the end of the grant cycle. As such I interface with my colleagues in the accounting departments and research and program administration office. I am also in close contact with the grants team at the CF Foundation as well as other sponsors.

At the Complex Care Center, we have been fortunate to have been the recipient of several awards from the CF Foundation, in addition to the annual Care Center grant.

I have been with the University for 18 years and with the Complex Care Center just prior to its inception in 2016. I have learned so much about childhood onset conditions including Cystic Fibrosis. I work with great individuals who are part of the team here. We are all striving to provide the best care to our patients!



## News from care center staff

At the November 2023 NACFC meeting, Vertex, maker of the current modulator medications, was able to share preliminary data from two of its Trikafta Extension Studies. The data looked at long term safety and tolerability of Trikafta, while also making sure it was still as effective as when it was started.

Safety is our first concern when starting a new therapy, especially newly approved therapies. These extension trials allow us to view safety for patients who are closely monitored while on therapy. Liver function blood test (LFT) monitoring is a routine part of care when starting a modulator due to the risk for increase in liver enzyme. In both trials fewer patients reported an increase in liver enzymes in the extension period of the trial compared with the initial study. This gives us confidence to monitor these blood levels yearly after the first year on therapy. Another positive trend was seen in the rates of rash. Extension study data confirmed that the risk of rash development decreases over time, with fewer patients presenting with rash in the extension study versus the initial study.

It is also important to consider if the effects seen in the initial studies were seen over longer periods of time. Both groups of patients had a decrease in sweat chloride and an improvement in lung function. For FEV1 (the number we always refer to in clinic after PFTs) an average increase of 10.1%. This data demonstrates that in our youngest patients, benefits from Trikafta are maintained throughout their time on treatment.

If you have questions about Trikafta or our other CFTR Modulators please reach out to your CF Care Team to discuss how these therapies may fit into yours or your child's care.

Jessica Kozakiewicz, Pharm.D, BCACP  
Clinical Pharmacy Specialist  
University of Rochester Specialty Pharmacy

## *A note about specialty medications*

The University of Rochester Medical Center has a Specialty Pharmacy that dispenses many of the specialty medications we use in CF care. At the care center, our experience has been the specialty pharmacy provides excellent care and follow up to our patients. They are able to deliver medications to the home and are very responsive to questions or concerns. If you have the ability to move your prescriptions to UPMC Specialty Pharmacy, our providers in both pediatrics and adult care wholly support that transition.

Some of the medications they can provide include:

Modulators

Pulmozyme

Hypertonic Saline

Inhaled Antibiotics

Please ask your provider or clinic pharmacist if you have questions.

## *What is a Health Home?*

A Health Home is a care management service model whereby all a person's caregivers communicate with one another so that all a patient's needs are addressed in a single support system. This is done primarily through a "care manager" who oversees and provides access to all the services a person needs to assure that they receive everything necessary to stay healthy, out of the emergency room and out of the hospital. Health records are shared among providers so that services are not duplicated or neglected.

Who is Eligible to be in a Children's Health Home?

Children from birth to age 21 must be enrolled in Medicaid AND meet eligibility criteria by having two or more qualifying chronic health conditions (check with your provider)

OR one of the following single qualifying conditions:

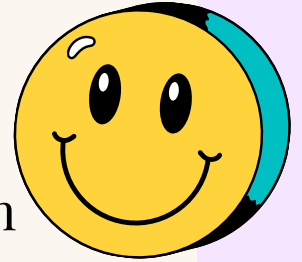
- HIV/AIDS
- Serious Emotional Disturbance
  - Complex Trauma
  - Sickle Cell Disease

If you are interested or want to learn more about the benefits of enrolling in a Health Home, reach out to your CF Center Social Worker or Health Care Provider:

Marcy Odell, LMSW  
(585) 275-2464



# FOR THE KIDS!

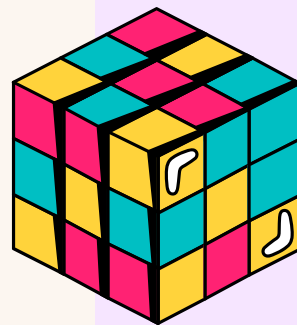


## Need Help Managing Your Child's Health Care Needs? Consider a Health Home...

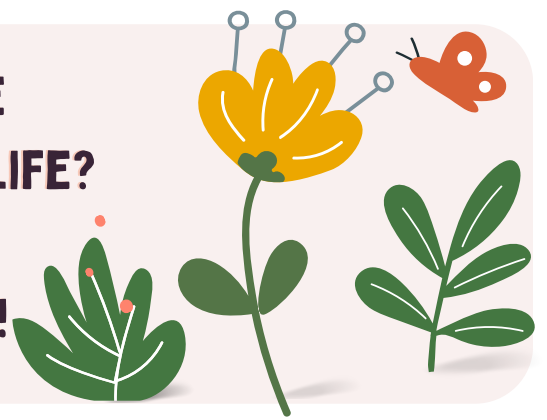
Many families spend countless hours on the phone being transferred from department to department trying to get critical answers and information regarding your child's services.

**If you have a child with New York Medicaid, Health Home Care Manager may be the answer.**

When you enroll in a Health Home, your Care Manager becomes your key point of contact in managing the services for your child. Families have the choice to select from several approved Children's Health Homes. In our area this service is known as CHHUNY.



**IS EXERCISE AND HEALTHY LIFESTYLE  
SOMETHING YOU WANT MORE OF IN YOUR LIFE?  
HAVE YOU HEARD OF BEAM?  
IF NOT, ALLOW ME TO INTRODUCE YOU!**



## **Our Mission!**

We're all about helping people with a health condition feel good, no matter where they are along their health journey.

We're supporting people worldwide to get that 'punch the sky' feeling every day by offering health-condition-specific exercise videos with fun, friendly and super-empathetic support.

An intro to Beam

With Beam, you can access fun exercise that's tailored for you and your health needs, online, any time, any place.

You can exercise along with on demand classes at a time that suits you or join a live class that allows you to interact with the instructor and other Beam members.

For those of you who would like an extra bit of motivation or social interaction, we've created groups where you can connect with physiotherapists, instructors and other people living with similar challenges to you. Let's lift each other up!

We know it's hard, but we want to help. Let us make things easier for you by bringing the experts, your community and your health studio to you, wherever you are.

In years past, CFF has funded BEAM subscriptions to make them available for people with CF at no cost. This is no longer happening but Until September 30, 2024, thanks to the generosity of the Helen M. Eisenmanan fund, through the BreatheStrong+ program, people with CF can access this amazing offering still at no cost!

Beam is an online platform for on-demand and live sessions designed specifically for people with CF. Sessions focus on exercise (all ages/all stages), wellness and education on various topics.

- Access for adults (18+) is free via private donor through 9/2024. Completing a session on Beam awards points for prizes through M4CF and BreatheStrong.

- Adult topics include bowel health, menopause, joint pain, GI health, preparing for pregnancy, etc.

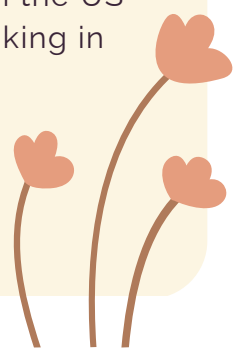
- Beam CF Youth is available for pwCF <18 yrs old and also free for kids in the US

- Kid topics include: preparing for PFTs, games, yoga, mindfulness, sneaking in exercise during vest treatments, etc.

- <https://beamfeelgood.com>

- ACCESS CODE for adults: BEAM-GLOBAL-CF-CLINICIANS

- ACCESS CODE for CF Youth: BEAM-GLOBAL-CFY-CLINICIANS



## Financial Assistance

If you cannot afford your medication after insurance pays its portion, you may be eligible for financial assistance through a Charitable Patient Assistance Program (CPAP).

Eligibility is based on your insurance, income, and medical diagnosis. Below are six CPAP organizations that offer financial assistance in the United States. Visit their websites or call to learn more.

Accessia Health Website: [www.accessiahealth.org](http://www.accessiahealth.org)

Toll-Free Number: (800) 366-7741

HealthWell Foundation Website: [www.healthwellfoundation.org](http://www.healthwellfoundation.org)

Toll-Free Number: (800) 675-8416

National Organization for Rare Diseases Website: [www.rarediseases.org](http://www.rarediseases.org)

Phone Number: (617) 249-7300

Patient Access Network (PAN) Foundation Website: [www.panfoundation.org](http://www.panfoundation.org)

Toll-Free Number: (866) 316-7263

Patient Advocate Foundation Website: [www.copays.org](http://www.copays.org)

Toll-Free Number: (800) 532-5274

The Assistance Fund Website: [www.taufactures.org](http://www.taufactures.org)

Toll-Free Number: (855) 845-3663.

## Reminder!

- As always, the Compass helpline from CFF can help point out many other ways to get help with insurance questions, co-payment and other services. [CFF.ORG](http://CFF.ORG)
- Compass is a personalized, one-on-one service that provides people living with cystic fibrosis and their families a partner in dealing with challenges related to life with CF, no matter where you are in your CF journey.
  - AIRS-accredited Compass case managers help with complex challenges, including understanding insurance basics, troubleshooting insurance coverage issues, seeking financial assistance for medical care and other living expenses, finding answers to legal questions related to work, school, disability/government benefits, and much more.
  - Get help by calling 844-COMPASS (1-844-266-7277), emailing [compass@cff.org](mailto:compass@cff.org), or submitting an online request form.

The last few years have brought a lot of changes to the CF community and Cystic Fibrosis Family Connection (CFFC) is no exception.

The most obvious change is the total overhaul of our website (<https://www.cffamilyconnection.org>) which was completed earlier this year. On the surface, we applied a new, more colorful template. Below the surface, we have changed the focus of the site to emphasize the programs offered by CFFC. You can find each of the programs listed in the main menu. (More on programs below.) Also our "Information" section now deals more in current events but we do provide links to sites with more comprehensive information about all aspects of life with CF.

We are still committed to our long-standing core programs: hospital help packets, clinic baggies and Education Day. Improved treatments for many with CF have reduced the demand for hospital help packets which gives us room in our budget for expanding our programs. In addition to increasing the Emergency Fund allocation, we are exploring other needs in the community through discussions with CF Center staff (both pediatric and adult).

Stay tuned!

If you haven't already, consider signing up for the CFFC email newsletter by sending your name and email address to [info@cffamilyconnection.org](mailto:info@cffamilyconnection.org). Produced once a month, the newsletter summarizes the information added to our website and Facebook page. We occasionally distribute significant, time sensitive information (like important surveys or schedule updates). For daily links to relevant - and interesting - information, you can follow us on Facebook (<https://www.facebook.com/CFFamilyConnection>)

## CFFC Emergency Fund

Working with CF social workers, CFFC provides emergency financial assistance for expenses temporarily beyond the family's means. For example, CFFC has provided funds for lodging for a transplant clinic visit, children's bedding and purchase of baby formula.

Given demands on CFFC's resources, the emergency fund program is restricted to families who are served by the Rochester CF Center. Emergency fund grants are limited to \$500 per year per individual. Awards may be disbursed as a single payment or a series of payments over the course of the year.

The criteria and application process are simple. It starts with a discussion of the emergency need with the CF clinic social worker, case manager or other member of the care team. The clinic staff notifies CFFC of the request for emergency assistance. The individual seeking help, or the care team member, sends an email to [info@cffamilyconnection.org](mailto:info@cffamilyconnection.org) providing the following information:

- The name of the individual requesting assistance
- A brief description of the purpose of the emergency assistance
- The amount requested
- The name of the payee for the emergency assistance [NOTE: payments can be made to third parties on behalf of the person living with CF.]
- The address to which the payment should be sent

CFFC may contact the applicant to clarify the request or seek additional information. CFFC sends an email to confirm the amount and timing of the award.



# From the CF Foundation

Cystic Fibrosis Foundation  
Rochester's Finest  
CF Family Ambassadors



## Finest Program Description

The Western New York/Rochester Chapter of the Cystic Fibrosis Foundation (CFF) honors Rochester's best and brightest young professionals with the Rochester's Finest program. These honorees show exemplary leadership, are active in their communities and have excelled in their profession or business. These leaders are not only making a positive local impact, but they are also committed to supporting the CFF mission – to cure cystic fibrosis.

Those who participate are given the opportunity to display their community involvement and highlight their professional achievements while raising funds to help provide all people with cystic fibrosis the opportunity to lead long, fulfilling lives.

The CFF Rochester's Finest campaign begins with a kick-off reception where the 2023 honorees and the CFF Rochester chapter leadership will meet and mingle. Each honoree will also be assigned a mentor and a CF ambassador. Throughout the campaign, one-on-one meetings and fun, informational networking events will take place. The campaign culminates with a celebration event in October where honorees are recognized.

Rochester's Finest will kick off in mid-July and wrap on October 19th. During that time, honorees will have an opportunity to meet a CF fighter and learn about life with cystic fibrosis.

## Goal of CF Ambassadors program

The goal of the CF Ambassadors program is to give each Finest honoree an opportunity to meet a CF fighter and learn about life with cystic fibrosis firsthand. Although we can share information on the science of cystic fibrosis, it is through the stories shared by CF Family Ambassadors that honorees can gain a true understanding of what life with cystic fibrosis looks like.

CF Ambassadors are adults with cystic fibrosis or families that include someone with CF.

As an ambassador, the family/individual agrees to:

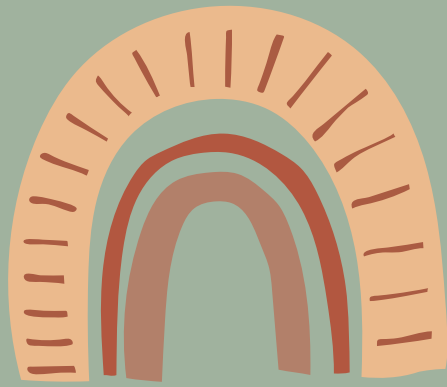
- Meet with the Finest honoree either in-person or virtually
- Share their CF story
- Answer questions about life with CF

Summary of the purpose of CF Ambassador Program

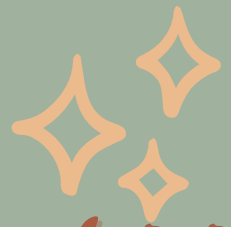
To give each Finest honoree an opportunity to make a personal connection to the mission through learning a CF Ambassador's cystic fibrosis story.

And

To give the Finest honoree a compelling story to share when asking for financial support of their participation in the Finest program.



*Quality  
Improvement!!*



## **GLUCOSE TESTING SURVEY**

We would like to thank those who completed the in-clinic survey to gather more information on the process of glucose testing. This allows us to start a discussion on how to make it easier for our patients! We were able to get a lot of valuable insight into what we can do to optimize this process. What we heard from a lot of our patients is that the biggest concern is making the time to be able to do the 2-hour test. We have worked together as a clinic to try to adapt and make this easier. We have started this month having patients take their glucose sample and begin their tolerance test before they come in for their regular clinic appointment with us. This way we can complete this test during your quarterly appointment once a year. It is important to us to be able to evaluate blood sugar levels in our patients as this can affect your treatment and lung health status. If you are due to complete a glucose tolerance test within the next few months, we may be contacting you to see if this may be an easier way to complete your glucose tolerance test. This will be available for select early morning appointments in clinic. Please let me know if you would like to discuss or make a plan around glucose testing in your next visit. Thank you for allowing me to help with your care!

Jade L Webb RDN CDN  
Complex Care Center Dietitian



# UPCOMING EVENTS



## SWINGING 'FORE' A CURE

**ROCCFA**  
CYSTIC FIBROSIS AWARENESS

**COBBLESTONE CREEK COUNTRY CLUB**  
100 Cobblecreek Rd.  
Victor, NY 14564

**ANNUAL GOLF TOURNAMENT**

**MONDAY, AUGUST 12, 2024**

**\$1,000 / Foursome**  
**\$250 / Individual**

Longest Drive, Closest to the Pin  
Putting Contest  
50/50 Raffles, Item Raffles,  
Silent Auction  
Skins: \$40/team,  
Mulligans (3): \$20/team

**\*\*\$10,000 Hole-in-One Contest\*\***

Cocktail Reception to Follow  
with Prizes

8 am -  
Registration,  
Breakfast &  
Practice  
Facilities  
Open

10 am -  
Shotgun Start

Lunch at  
the Turn

Unlimited Beverages / Open Bar

**CYSTIC FIBROSIS FOUNDATION**  
PROUD SUPPORTER  
cff.org

For more information, or to register, contact Mike Sellars: (585) 481-4622 or MSellars@ROCCFA.org  
ROC Cystic Fibrosis Awareness Inc. is a registered 501(c)(3) | EIN 87-3371318



**GREAT STRIDES**  
CYSTIC FIBROSIS FOUNDATION

LACE UP. WALK. CURE CYSTIC FIBROSIS.

**MAY 19, 2024**  
**Genesee VALLEY PARK**  
**CHECK-IN: 10:00 AM**  
**WALK: 11:00 AM**  
**SIGN UP HERE!**

# WE ARE HERE TO HELP!

## 5 WAYS TO PARTNER WITH YOUR CF CARE TEAM

### *For Individuals Living with Cystic Fibrosis*

Managing cystic fibrosis (CF) may feel like a balancing act where the demands of CF are just one part of your busy day. By sharing what matters most to you, you can partner with your care team to help find that balance. Consider using these tips to help you prepare for your clinic visits.

1

#### **Be Open and Ask for Help With Your Care Plan**

Share openly and honestly about your care needs so your team can work with you.

- You are an expert in your care and know what works and doesn't work for you.
- If something's not working, share that with your team so you can come up with solutions together. Your team is there to help you.

2

#### **Share What's Going on in Your Life**

*When life changes, your care plan may need to change too.*

- Sometimes, life can get in the way of your daily care — and vice versa.
- Your team knows that CF is just one part of your life. Share celebrations and challenges in your life with them so they know what else is going on.

3

#### **Communicate Outside of Clinic**

*You manage CF every day, so why wait until clinic to ask questions?*

- CF care happens in real time; reach out to your care team with ideas or questions.
- If something urgent is going on, connect with your team for advice and next steps.

4

#### **Invite Other People Into Your Care Planning**

*Managing CF doesn't have to be a solo activity.*

- You are the one managing your CF, but you don't have to do it alone.
- Think about who else in your life can join you on your journey of managing CF and invite them to participate in your care discussions in a way that works for you.

5

#### **Approach Difficult Conversations with Respect**

*You and your care team are motivated by a shared goal: improving your health.*

- Your team is there to help you manage CF, but, it's not always easy to work together.
- Even when it might be difficult, think about how you can work with your team to find a plan that works for your life and that will help you meet your medical goals.

# Wash up!

Maintaining daily therapy and attention to infection control remain very important elements of care when you are living with CF. A reminder about what medications are often prescribed for lung health, along with guidelines about cleaning equipment are always helpful to review.

## Cystic Fibrosis: Suggested Order of Therapy for Daily Care

Please note: you or your child may not use all of these medications or therapies



### Therapy #1: Bronchodilator

What? albuterol (Proventil®), ProAir®, Ventolin®, levalbuterol (Xopenex®)

How? Inhaler or nebulizer

Why? To open up the airways by relaxing the muscles around them. This helps to widen the airway and make air flow easier into and out of the lungs. This assists other medications getting into the lungs better, and mucus to move out easier.



### Therapy #2: Hydration

What? hypertonic saline (Hypersal®, Pulmosal®)

How? nebulizer

Why? Draws water onto the airway surface making airway secretions less thick and sticky, and helps cilia have enough room to move. Cilia are little hair like structures whose job is to move the mucus by moving together in a waving pattern. Cilia help move the mucus up the system of airways toward the larger airways where mucus can be coughed out.



### Therapy #3: Mucolytics

What? dornase alfa (Pulmozyme®), Acetylcysteine (Mucomyst®)

How? nebulizer

Why? Making mucus less sticky and thick will make it easier for you to move the mucus and cough it up and out. Less mucus means less chance for more bacteria to grow in the lungs.



### Therapy #4: Airway Clearance Therapies

What? Moving mucus up and out!

How? Chest percussion, OPEP (AerobiKa®, Acapella®, Flutter valve®) PEP device

Breathing techniques: autogenic drainage, active cycle breathing, huff cough

Vest systems: TheVest®, inCourage®, Smart Vest®, Affio Vest® Monarch®

Other: percussor or Vibr Lung®

Why? Moving mucus up and out of the lungs is the most important component of your airway clearance therapies. After all the hard work you've done taking your medications, huff and cough that mucus up and out.



### Therapy #5: Inhaled Antibiotics

What? aztreonam (Cayston®), tobramycin (TOBI®, TOBI® Podhaler™, Bethkis®), colistimethate (Colistin®)

How? nebulizer

Why? Antibiotics help to kill the bacteria that can grow in the mucus. Always take ALL of the antibiotics that the doctor has told you to take.



### Therapy #6: Corticosteroids (if you have an asthma diagnosis)

What? Inhaled steroids: budesonide (Pulmicort®), beclomethasone (Pulmicort, QVar®), fluticasone (Flovent®), mometasone (Asmanex®) ciclesonide (Alvesco®)

Inhaled corticosteroid and long acting bronchodilator: (fluticasone and salmeterol

(Advair®), budesonide and formoterol (Symbicort®), fluticasone and vilanterol

(Breo®), mometasone/formoterol (Dulera®).

How? inhaler/nebulizer

Why? Airways can have swelling in them from mucus and recurrent infections.

Corticosteroids will help reduce swollen inflamed airways. Don't forget to rinse your mouth after taking them!

This information meets the guidelines and standards of the Cystic Fibrosis Foundation's Education Committee.

## Disinfection of Respiratory Equipment

### Heat Methods:

Place in boiling water and boil for 5 minutes.

Place in a microwave-safe container submerged in water and microwave for 5 minutes.

Use a dishwasher, if the water is 158 degrees or more, for 30 minutes.

Use an electric steam sterilizer. (baby bottle)

### Cold Methods:

Soak in 70% isopropyl alcohol for 5 minutes.

Soak in 3% hydrogen peroxide for 30 minutes.

Rinse off the cold-method disinfectant using sterile water, not tap water.

Air-dry the nebulizer parts before storage.