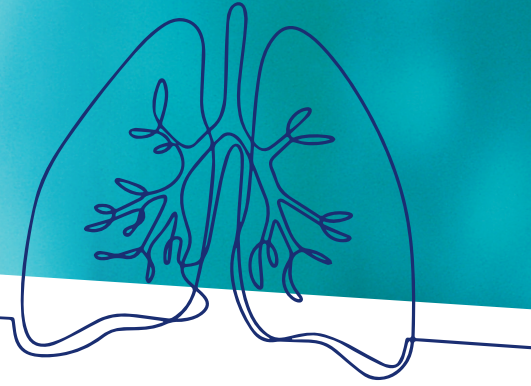


# CYSTIC FIBROSIS

## Patient & Family Advisory Council



### Spring Issue 2024

The NH CF Patient and Family Advisory Council is a group of CF Patients, their families and caregivers and members of the CF Care Team at Dartmouth Health. We meet virtually every two months and collaborate on projects that will enhance CF care.

### Our Mission

The NH CF Patient and Family Advisory Council seeks to enhance the care and quality of life of the CF population. The NH CF PFAC works in partnership with the CF Care Center to advocate on behalf of parents/caregivers and patients for the best quality of care.

Please email [nhcfpatientfam@gmail.com](mailto:nhcfpatientfam@gmail.com) if you're interested in being part of this group.

Newsletter team: Kerri Boucher, Paula Garvey, Kristin McCarthy, Mickey Noyer, Ashlee Robinson, and Sarah Vooris

### What's inside?

March on the Hill Recap

Move-a-Palooza Update

What is CFRD?

XoC

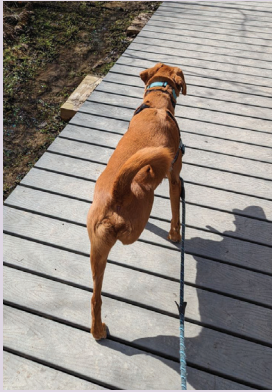
and much more



Follow  
Us



# CF Community News



Meet our CF community's pets



## EMPOWERING TRANSITION

### Navigating CF Care from Childhood to Adulthood

Join us for an interactive virtual event dedicated to facilitating a smooth transition from pediatric to adult care for individuals with cystic fibrosis (CF). This event aims to foster a supportive environment where we discuss strategies to encourage medication and therapy compliance and promote independence.

#### Panel Discussion

**Parent Perspective: Navigating the Transition Journey**  
**Team Member Guidance: Supporting the Transition Process**  
**Adult with CF: Personal Experiences and Insights**

#### Interactive Session

Share your experience  
Seek advice from experts  
Learn about effective solutions

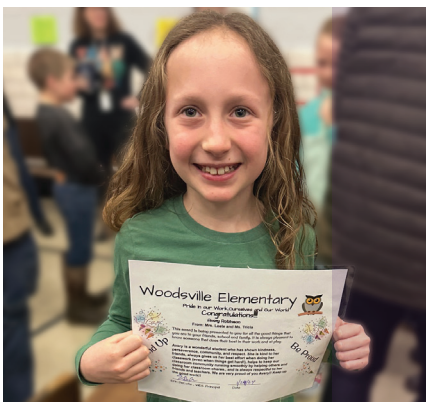


#### All Are Welcome:

Whether you're a patient, caregiver, healthcare professional, or simply interested in learning more about CF care transition, your presence is valuable

June 25th 7pm  
via Zoom

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



Congrats to Avery who received a *Stand Up and Be Proud* award in January for her kind and respectful demeanor in school!

Way to go, Avery!

# CF Center News

## Northern New England Cystic Fibrosis Consortium Annual Meeting Recap

### April 4 & 5 | Portland, Maine

by Paula Garvey

Every year the Northern New England Cystic Fibrosis Consortium meets to exchange knowledge, discuss ongoing quality improvement initiatives, and delve into the latest research findings. This collaborative effort involves CF centers from Maine, New Hampshire, and Vermont, with the shared goal of enhancing care within our centers. This year's meeting, initially planned to be held in Portland, Maine, faced a challenge as the April snowstorm disrupted travel plans, prompting many participants to join remotely.

Despite the logistical hurdles, attendees were thrilled to engage in breakout sessions, fostering connections and exploring potential collaborations. One such session involved members of the Maine and NH Patient and Family Advisory Councils (PFAC), where discussions centered on collaborative opportunities and the significant time commitment that CF demands from patients and families.

The agenda was packed with insightful presentations covering various aspects of CF care and research. Topics ranged from diabetes screening and fecal elastase monitoring to addressing food insecurity and boosting vaccine rates. A notable highlight was the quality improvement project focusing on the transition from pediatric to adult care at DHMC.

Whitney Brown, Senior Director of Clinical Affairs at the Cystic Fibrosis Foundation, shared research on aging with CF. Key takeaways included the growing population of adults with CF, the heightened risk of certain cancers necessitating diligent screening, and emerging concerns regarding bone health, diet, obesity, and kidney disease.

For a deeper dive into colorectal cancer risk among CF patients, attendees were directed to an informative video provided by the CF Foundation ([video link below](#)).

Dr. Lael Yonker, Assistant Professor of Pediatrics and Co-Director of the MGH Cystic Fibrosis Center at Massachusetts General Hospital, presented research on the impact of CFTR modulators on mental health. This complex area warrants further investigation, given the higher prevalence of mental health conditions among CF patients compared to the general population. Questions abound regarding the potential interplay between gut health and mental well-being, highlighting the need for comprehensive research efforts in this domain.

In reflecting on the day's proceedings, it's evident that our CF community is exceptionally fortunate to be supported by dedicated, knowledgeable, and compassionate teams. Their unwavering commitment to improving the lives of patients and families underscores the strength of our collective efforts in the fight against CF.

If you have any questions about NNECFCC please ask your care team.



Watch the informative video on colorectal cancer risk in CF patients



# Experience of Care (XoC) Survey!

by Sarah Vooris

Completing an Experience of Care (XoC) survey is easier than ever in 2024. Simply scan the QR code or use the URL link provided during your CF clinic visit to take a survey.



## Remember, the XoC survey:

is short.

covers in-person and virtual visits.

is anonymous, it will not be linked to you or your child's name.

## XoC survey updates and information on the impact your voice is having at our clinic may be found:

in future PFAC newsletters and on the PFAC website.

within social media updates from PFAC and our center.

at Family Education Nights.

by joining PFAC meetings when possible.

*If you have questions about the survey, please reach out to [nhcfpatientfam@gmail.com](mailto:nhcfpatientfam@gmail.com) or talk to a CF team member at your next clinic visit.*

# 17th Annual March on the Hill for Cystic Fibrosis

by Bob Burnham

Hope in Action! The 17th Annual March on the Hill underscored the commitment and strength of the CF community to advocate for crucial legislation. I was one of 350 advocates from 45 states that convened in Washington, DC, to engage with 214 congressional offices.

A highlight of the event was the opportunity I had to directly participate in advocacy efforts alongside fellow CF parent Christine, and CF Foundation Staff members Terry Waite (Mass and RI Chapter) and Adina Rubenstein (Public Policy Coordinator, Bethesda). Together, we visited the congressional offices of Senator Peter Welch (VT), Senator Bernie Sanders (VT), Senator Jack Reed (RI), and Representative Gabe Amo (RI). These meetings were not only productive but also deeply meaningful, as we were able to personally convey the challenges faced by the CF community and the importance of the PASTEUR Act and the HELP Copays Act to people with CF and families.

Our meeting with Senator Reed's staff was particularly productive because Christine had met with the senator and his staff several times at previous March on the Hill events and at his office in Rhode Island. Seeing the impact of that personal history on their discussions, and the senator's engagement on both acts was a powerful demonstration of the value of being a committed advocate for the long term.

I plan on returning to DC as often as I can to participate. Through our advocacy, we are not just fighting for legislative changes today; we are paving the way for a future where individuals with CF can lead fuller, healthier lives. As we await the progress of the PASTEUR and HELP Copays Acts, our commitment to supporting each other and advancing the cause of the CF community remains unwavering.



▶ To learn more on how you can get involved:  
[cff.org/get-involved/ways-advocate](https://cff.org/get-involved/ways-advocate)

# What is CFRD?

Cystic fibrosis-related diabetes (CFRD) is one of the most common complications of CF in adults. CF Foundation Patient Registry data shows that about 19% of people with CF have CFRD.

You may be familiar with type 1 and type 2 diabetes. CFRD is unique to people with CF, though it shares features with both type 1 and type 2 diabetes. In CFRD, the pancreas does not make enough insulin, similar to type 1 diabetes. People with CFRD can also develop insulin resistance, which occurs in people with type 2 diabetes. CF can cause scarring of the pancreas because of thick, sticky mucus. The mucus prevents the pancreas from producing normal amounts of insulin, so people with CF can have insulin insufficiency and sometimes even become completely deficient. People with CFRD can experience insulin resistance especially when they are ill, taking steroids, or in certain circumstances (like pregnancy).

In the past, many problems seen in type 2 diabetes, such as obesity, high cholesterol, and heart disease, were not thought to be a part of CFRD. However, since the introduction of CFTR modulators, people with CF are living longer and their symptoms are beginning to resemble those of the general population. Issues such as obesity, high cholesterol, and heart disease are occurring more frequently. Being overweight or obese has not traditionally been a cause of insulin resistance in CF, but this is changing with CFTR modulators.

It is important to manage CFRD to prevent complications such as nerve damage, retinal (eye) damage, kidney damage, and to help prevent weight loss, lung exacerbations and infections, and improve survival. The goal is to keep your blood sugar (also referred to as blood glucose) at normal—or near-normal—levels and to eat a balanced, healthy CF diet as recommended by your CF and diabetes care teams.

Your CF and diabetes care teams can make a plan to help you successfully manage living with CFRD.

**For more information about CFRD please contact your team or**

- **Gretchen Kidder**, APRN, Endocrinology, Lebanon
- **Krithi Ramesh**, MD, Endocrinology, Manchester
- **Laurie Campbell**, RD, CSP, LD, CDCES,  
Nutritionist and Diabetes Care and Education Specialist, Manchester

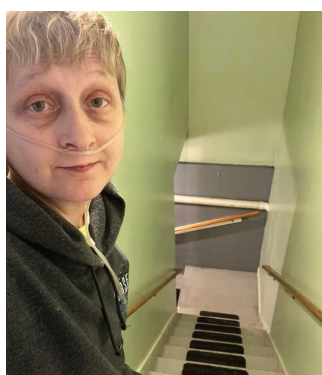
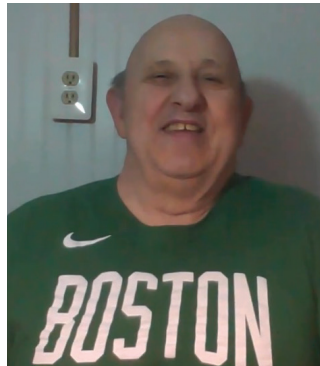
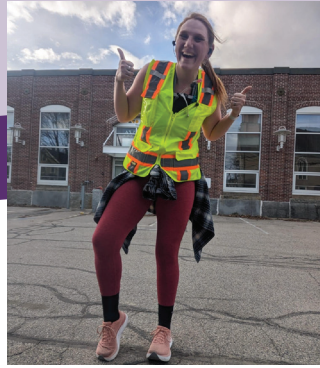
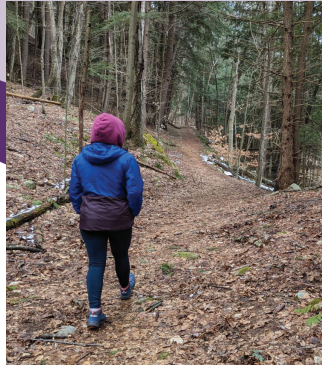
[cff.org/managing-cf/cystic-fibrosis-related-diabetes](https://cff.org/managing-cf/cystic-fibrosis-related-diabetes)

# MOVE-A-PALOOZA



MOVE-A-PALOOZA

NH CF PFAC



by Bob Burnham and Paula Garvey

The story of CF Move-a-palooza began with a conversation during the annual Dartmouth Health CF Team retreat in September 2022, where concerns about the rising obesity rates within the CF population were discussed. Looking for ways to promote a healthier and more active lifestyle for CF patients and their families, the idea for an event took shape. Our PFAC organized a meeting and set up a committee composed of PFAC parents, an adult with CF, and a CF Team member. This initiative materialized into the inaugural Walkorama in 2023 thanks to the support of a grant from the Boomer Esiason Foundation. What started as a small-scale event has since flourished into CF Move-a-palooza 2024, a recurring and evolving event aimed at encouraging the CF community to embrace physical activity while enjoying themselves.

To be more inclusive, we decided to rebrand the event this year as CF Move-a-palooza 2024. Participants are encouraged to report all forms of activity on a weekly basis. Participation is open to all CF patients receiving care at Dartmouth Health, along with their family members, friends, caregivers, and CF care team. Participants signed up for the event and registered their activity weekly. CF Move-a-palooza 2024 commenced on March 17th and will conclude on May 5th. Thanks to the generous grant from The Boomer Esiason Foundation, CF Move-a-palooza 2024 offers exciting prizes to participants. Each participant received a beanie hat adorned with the event logo, with additional prizes awarded through draws for participation, photo submissions, and other engaging interactions.

## Here is some feedback from our amazing participants:

- In our first week, 37 participants reported an average of 400 minutes. The reported grand total equaled about 15,000 minutes of movement! As impressive as the minutes were, it was the great moments shared that really characterized the first week: MJ was very excited for "Karate!" Tovah, "Walked around NYC on St. Patrick's Day!" MickeyN went kayaking in Florida. KaylaC ran her first 7 mile run! And CadieF "Worked on my back tuck a lot!"
- In week two Move-a-palooza saw a flurry of activity! Jordan 9 kicked things off with the motto, "every day is a highlight!" Julia chimed in, calling our region "the most magical place on earth" for moving (we can't disagree!). Tovah soaked up the sunshine, "walking around the farmer's market," while Robert got creative with his steps, "walking while cooking and at the hospital!" A special shoutout to Mickey, who fell off her bike but powered through with an impressive 412 minutes this week!

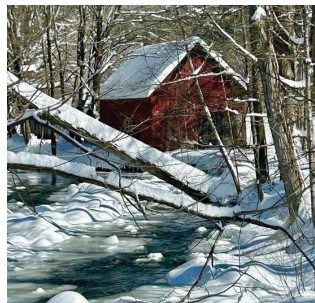
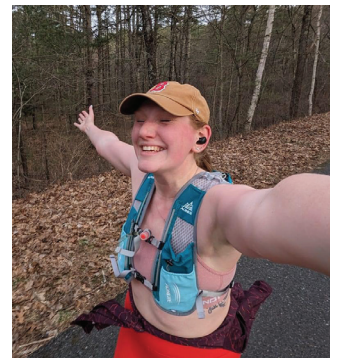
We await the reports from week three as an unexpected snowstorm may have changed our outdoor activity plans.

We are so grateful to everyone who is participating in CF Move-a-palooza 2024. Through shared experiences, support, and encouragement, participants are not only embracing a more active lifestyle but also forging lasting connections within the CF community. Check out our social media for the latest updates.

[Check out FREE Yoga for people with CF and their families](#)

And if you are looking for some after workout snack recipes, find great ideas [here](#).

A huge thank you to our organizing committee: Kerri Boucher, Bob Burnham, Danielle Cantin, Paula Garvey and Kathy Sabadosa.





# Molly's Corner

## Spring and New Beginnings!

**Molly J. Stark, MSW, Social Worker**  
Pediatric Specialties

Spring is a time of rebirth, rejuvenation, and renewal. I don't know about you, but just like the trees and plants around us, I find myself changing with the seasons. The winter provides us with rest, slowness, and quietness, but it can also be easy in the winter months to get stuck in the monotonous days. So, with the warm air coming soon, we may find we have the motivation and the opportunity to embrace the full sun, and step out into something exciting, bright, and colorful.



One of my favorite quotes states, "The best time to plant a tree was 20 years ago. The second best time is now." This quote is a helpful reminder to not let the fact that we haven't done something yet, keep us from starting today—that today and tomorrow and next month and next year can all be the first time we try something new. It is never too late! Below is a list of some fun family friendly and solo outdoor ideas to help you either do an activity for the first time this spring or revisit a past hobby.

Today is a new beginning and just like the flowers and trees, you also have the capacity to start anew and decide how you will flourish and blossom! Where will this spring take you??

**Visit a beach or lake**

**Visit a playground**

**Roller-skate**

**Play yard games**

**Play tennis**

**Stargaze**

**Birdwatch**

**Explore a nearby town**

**BBQ at the park**

**Read outdoors**

**Photography**

**Draw or paint outside**

**Make tie-dye**

**Bike**

**Start a collection**

**Nature scavenger hunt**

**Start a garden**

**Go fishing**

**Have a picnic**

**Making chalk murals on  
the sidewalk**

**Fly a kite**

**Kayak**

**Hike**

**Gather around a fire pit**

**Yoga**

**Camp**

**Go on a nature walk**

**Paint rocks**

**Run**

**Play catch**

**Go berry picking**

**So many more...!!**

# Save the Dates!



## PFAC Meetings

Mon, May 6 @ 7 pm

Tue, Sep 10 @ 7 pm

Mon, Nov 4 @ 7 pm

## Transition Group Meetings

Tue, June 25 @ 7 pm

Tue, Oct 1 @ 7 pm

Tue, Dec 3 @ 7 pm

## NACFC 24 Boston

Sep 26–28

## Pediatric CF Education Night

Wed, Oct 16

3rd Annual



The Rock CF Foundation is back for the 3rd Annual Rock CF Hike 2 Breathe this May for Cystic Fibrosis Awareness Month! Emily Schaller will be in our area hiking Mount Willard on May 9th.

The Rock CF Foundation's Hike 2 Breathe is a virtual hike from your chosen location. Hike a mile in a walk down the block, stroll in urban or rural areas, on trails, up mountains, or anywhere that suits and challenges you. Hike 2 Breathe spans the entire month of May in celebration of Cystic Fibrosis Awareness Month.

Registered hikers receive a Rock CF x Hike event shirt and a custom hat. All participants will be sent their virtual gear in April. Additional gear awaits those who choose to fundraise for the Rock CF Foundation through their virtual hike.

For people with CF, use code **CFROCKSTAR24** for 100% off your registration cost! *Please note: This code is only for those living with CF.*

All participants are encouraged to share their experiences with Rock CF and their family/friends via Facebook, Instagram, Strava, etc. Be sure to tag @LetsRockCF and use the hashtags #RockCF and #Hike2Breathe for the Rock CF Foundation to see/share photos, too.



Learn more & signup at:  
[runsignup.com/Race/MI/Detroit/RockCFsHike2Breathe](https://runsignup.com/Race/MI/Detroit/RockCFsHike2Breathe)



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MAINE  
NEW HAMPSHIRE  
& VERMONT!

COMMUNITY, FUN AND CONNECTION

**Register to join us by scanning here!**





# RIDE TO CURE CF



## Seacoast Safari Cycle for Life July 13, 2024 - Kittery, Maine



Tributary Brewing Company  
Choose from 35, 65, and 100 mile routes  
Check-in: 6:30AM Start time: 7:30AM  
Fully supported ride with rest stops, lunch,  
and post ride entertainment!

Register **HERE:**



Northern New England Chapter Phone:  
**800-757-0203**

Email:  
**Northern-NewEngland@cff.org**

\*This QR code will take you to the Northern New England Chapter Calendar of Events.\* You may reach out to the chapter at northernnewengland@cff.org for contact information to receive a printed copy.\*

[fightcff.org/seacoastsafari](http://fightcff.org/seacoastsafari)



## BOW LAKE DAM 15K/5K RACING TO CURE CYSTIC FIBROSIS

»»» JUNE 1, 2024  
STRAFFORD, NH  
**YEAR 16!**



[BOWLAKEDAM15K5K.COM](http://BOWLAKEDAM15K5K.COM) <<<

**TEAM  
BOOMER**  
FIGHTING CYSTIC FIBROSIS



*BREATHE*

**WEEK**

May 4th - May 11th

*Join Us!*

Signup at [esiason.org/events](http://esiason.org/events)

