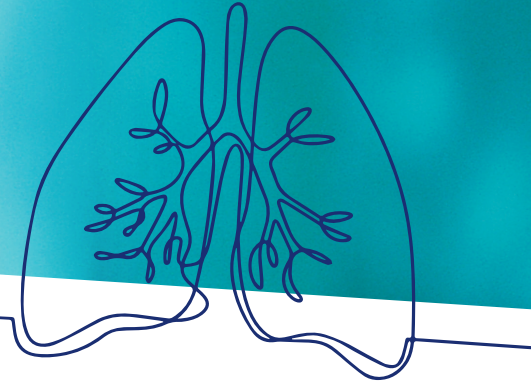


CYSTIC FIBROSIS

Patient & Family Advisory Council

DHMC CF Center



Winter 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 if you're interested in being part of this group.

Newsletter team: Kerri Boucher, Roni I. Finkelstein, Paula Garvey, Kristin McCarthy, Mickey Noyer, Ashlee Robinson, Emily Seamans, and Sarah Vooris

What's inside?

CF Family Night Recap

North American
CF Conference

Transitions Group

Research Update

and much more



Follow
Us



CF Community News

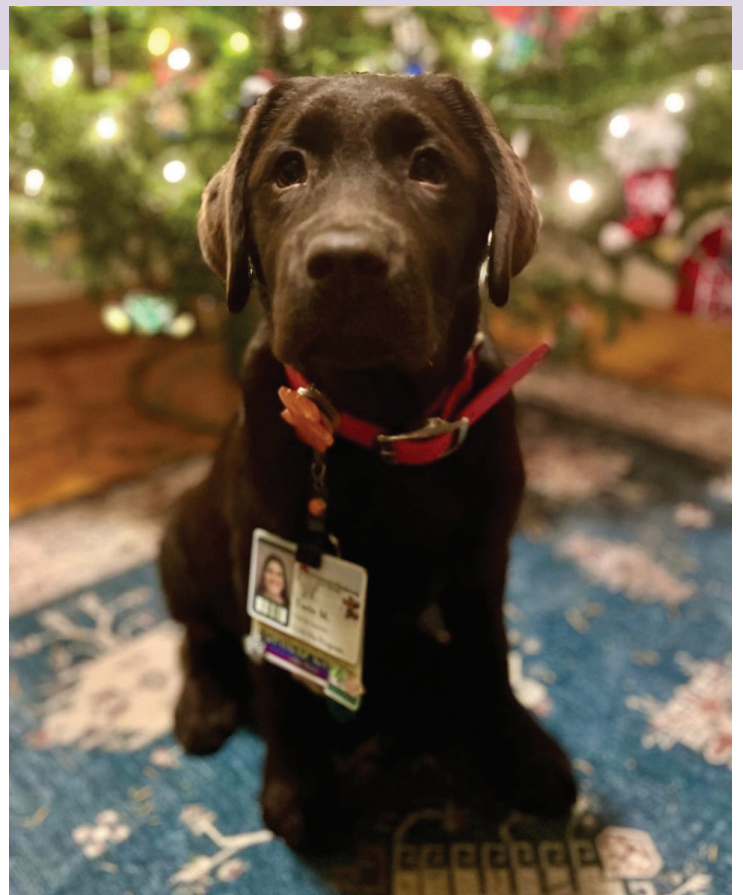
Welcome Winnie and Moose!

The Child Life Program will welcome two new members to their team in late 2024. Winnie and Moose walk on four paws instead of two legs and are called Facility Dogs. A Facility Dog is specifically trained to serve patients and families alongside their trained employee handler.

Unlike our therapy dogs who provide comfort and affection with their volunteer owner, facility dogs partner with a working professional to meet individual treatment goals and provide direct interventions to patients. Their training is similar to that of a service dog and begins when they are puppies. Our facility dogs and their handlers will be in school for a little over a year to help them learn all they need to know to be ready to work. Winnie will work at DH Manchester and Moose will work at DHMC.

To learn more about facility dogs check out these websites:

- canine.org
- coldspringhealingpaws.org



CF Patient & Family Education Night

Our annual CF Patient and Family Education Night was held in Concord in November. We were delighted to gather to share information and take the opportunity to connect with our team, pharmaceutical representatives and the CF Foundation. The amazing Nicholas Kelly shared his wisdom and gave us insight into his life with CF.

Our guest speaker, Nick Kelly, is also an author. One of our younger CF friends reviewed his book.



**Avery, age 8, tell us about Nick's book:
*The Adventures of Miss Messy Suzie McGoo & Her Respiratory Zoo***

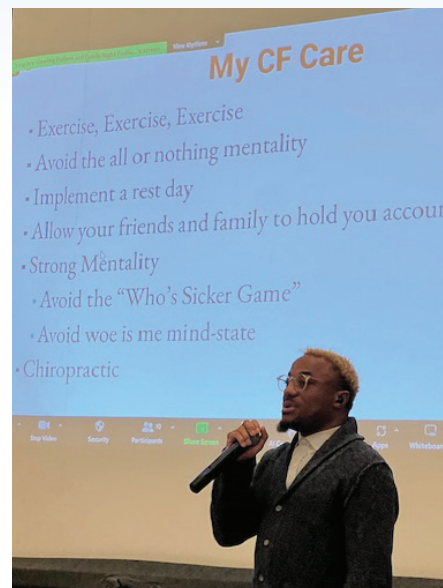
What was your favorite part of the book?
My favorite part was when all of Suzie's little animal creatures came to life. My favorite character was the Antibiotic Aardvark because he has the hardest job of all and isn't always included in Suzie's CF routine. Plus he's cute!

What did you learn about CF that you didn't already know?
I learned that our CF medicines have to be taken in a certain order. I also learned that there are yucky germs in CF lungs.

After reading this book, do you think it's really important to do your CF treatments? Why?
Yes! Because if you don't, you could get really sick.

What more do you want to tell us about the book?
It made learning about CF really fun and silly, with cute characters!

Please ask Childlife if you would like a copy of Nick's books and check out his [website](#)



If you missed our CF Education Night you can watch the recording [here](#) <<<

NACFC

North American CF Conference



The North American CF Conference took place in Phoenix, AZ in November 2023. Thousands of health care professionals, families, scientists and interested parties from across the CF community, representing 33 countries gathered to learn about the latest updates in the CF world. Our Dartmouth Health CF Team attended and presented at the conference. The three day event was packed full of learning opportunities, presentations, discussions and networking opportunities.

Check out [this video](#) from the CFF to see highlights from the event. Connect with your team if you have any questions.



Look for a new way to take the Experience of Care (XoC) Survey!

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

Most importantly, the feedback and comments captured in the XoC survey will let us know what is most important to you and your family. For example, past survey data from patients and families at our CF center prompted:

- a review of care center communication tools.
- inquiries into how to improve efficiency and reduce wait time.
- support for the development of a stronger adolescent to adult care transition process.
- increased knowledge of best practices to continue.

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

- in future NH CF PFAC newsletters and on the NH CF PFAC website.
- within social media updates from NH CF PFAC and our center.
- at Family Education Nights.
- by joining NH CF PFAC meetings when possible.

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

XoC Survey At Work

The primary goal of the XoC survey is to let the CF care team know what is going well and to help them make changes and improve the care you or your child receive. Feedback from past XoC surveys substantiated the need for improvements in the process of transitioning adolescents from the pediatric to adult program at our center. The CF care team initiated the work in 2023, with the project continuing over the next year or more.

Transitions Group

Spurred on in part by the transitions improvement project at our center and by a group of parents chatting at a recent Great Strides walk, our NH CF PFAC decided to offer a place to connect. The Transitions Group is an informal space for those wanting to chat with others as their loved ones begin taking on more and more of their CF care with the intent of independence and joining the adult care team. We have a wealth of information and advice we can offer each other.

The Transitions Group meetings will have no agenda and are open to everyone wanting to learn and share experiences. We all, from parents of newborns through adults with CF, have something to offer and/or learn from one another.

Our next meeting is February 6 at 7 pm. All meetings are virtual.





If you have a minute,
[here is an interesting article](#)



Caregivers of teens - let's connect!



Parenting teenagers can be challenging. CF adds an extra layer of complexity. Please join us to chat about relevant topics to caregivers of teens with CF, such as transitioning from pediatric to adult care and more.

-  Join us online every eight weeks
-  Talk with other caregivers of teens with CF
-  No commitment - come once, a few times or every meeting
-  Learn what to expect at CF clinic visits and beyond

"You are not alone"

For more information talk to your CF Team,
email nhcfpatientfam@gmail.com
or check out www.nhcfpac.com

Transitions Group Meetings

Tue, Feb 6 @ 7pm

Tue, April 2 @ 7 pm

Tue, Aug 6 @ 7 pm

Tue, Oct 1 (after NACFC!) @ 7 pm

Tue, Dec 3 @ 7 pm

NH CF PFAC & CF Community News

NH CF PFAC

New Hampshire CF Patient and Family Advisory Council will meet five times this year. We would be delighted if you could join us. Email us for the Zoom link prior to meetings (email below).

NH CF PFAC Meetings 2024

Mon, Jan 8 @ 7 pm

Tue, Mar 5 @ 7 pm

Mon, May 6 @ 7 pm

Tue, Sep 10 @ 7 pm

Mon, Nov 4 @ 7 pm

Our goal is to enhance the care and quality of life of the Cystic Fibrosis community at DHMC.

Check out our Newsletter Website and Social Media 504 Plan information Fitness events Newborn kit Welcome kits CF Education Night

NH CF PATIENT AND FAMILY ADVISORY COUNCIL IS A GROUP OF CF PATIENTS, FAMILY MEMBERS, CAREGIVERS, AND PROVIDERS AT DHMC. WE AIM TO ENHANCE THE LIVES OF OUR LOCAL CF COMMUNITY

CYSTIC FIBROSIS PATIENT AND FAMILY ADVISORY COUNCIL

CYSTIC FIBROSIS
Patient & Family Advisory Council
DHMC CF Center

If you have any ideas on how we can help our CF community, please email: nhcfpatientfam@gmail.com

TD Bank Affinity Program

Support our CF Patient and Family Advisory Council by asking your local TD banking agent to link your accounts to the NH CF PFAC Inc through its Affinity Banking program. Our specific code is AJ332. Eligible accounts include business and personal, checking, savings, money market, CD, and retirement. We will receive \$50 for every new checking account and \$10 for every existing checking account linked to us. For savings accounts or CDs we receive 1/10 of 1% contribution based upon participants annual average balances.

Please note: NH CF PFAC will not receive any information from TD Bank regarding your account balances or any other personal information. This program is run solely through TD Bank.



Bridge Of Hope

Do you have medication that you no longer need or use that has not expired? Bridge Of Hope needs your help! Bridge of Hope is an organization that helps CF patients from underserved parts of the world. They provide free medical care and donated medications to CF patients. If you have extra medication that you cannot use and would like to donate, please contact Bean at Bridge of Hope. It's easy! They will provide a FedEx label to ship unused, unopened, and not expired enzymes, MVW vitamins, Pulmozyme, and modulators. Thanks in advance for helping patients in need. Please check out the link below or email Bean Corcoran at beancorcoran.cff@gmail.com for more information. Check out their [website](#)

Research Studies

A CF Patient's Perspective

by Kerri Boucher

There are many reasons why those of us with CF may want to participate in clinical trials. For some of us, it's a way to give back to the community, follow in the footsteps of those who participated in earlier trials for CF treatments, or possibly a way to make extra money. Whatever those reasons are, they are always a personal decision that we make for ourselves with the help of our care teams and loved ones.

I personally have participated in many trials and research studies. At first I was very unsure if this was something that I wanted to do. I thought my health was okay—I was able to work, had some hospitalizations, and my lung functions were stable—so adding new treatments that were not FDA approved was not something I was looking to do. That changed when I found out one of my gene types made me eligible for the Kalydeco trials.

I had been offered the chance to participate in the phase 2 Kalydeco trial but turned it down. When the next phase came around, I had to really rethink my “why.” I thought about all of the CFer's that would love to have this chance, like my sister and some friends that were no longer with us. I also thought about all the time my family had put into raising awareness and funds just to help me have this opportunity to potentially have a chance at better health. After discussions with my family and the research team, I decided to be evaluated for the study and was accepted after completing a screening visit which included tests such as EKG, Labs, and a physical.

The phase 3 Kalydeco trial took place over two years. The first year, I had placebo which both myself and researchers did not know for sure at the time due to the “blinding” of the study. I had no changes in my health. I still had to complete all of the study visits, questionnaires, and testing during that time. After the first year, I was offered the chance to move to the open label study which was the same protocol as the first. But, now I knew I had the real medication and noticed positive changes in my health within a few days.

My experience with clinical trials has been very positive. Each of the research teams that I have worked with were extremely knowledgeable and truly wanted you to receive the best care possible. Another factor you may want to consider is there are many types of trials, some are one-time visits, others you may be able to coordinate with your regular CF clinic visits, and others like the modulator trials, may require more visits to the research center than your quarterly CF check-ins. With the modulator trials, there is a bit of a time commitment for regular visits but after a while on the drug or placebo, the visits spread out and some even become phone check-ins. All studies are also monitored for safety by an independent medical advisor so you will be safe. You are also free to leave a study if you need to by notifying your research nurse and following protocol to end your participation.

If you are interested in participating in CF research, I recommend that you speak with your Research Nurse, or any member of your CF Team for more information. Any type of study you participate in will help to improve care for you and all those living with CF.

Research Update

Gene Therapy

by Dana Dorman

What does the Cystic Fibrosis Foundation and Michael Jordan have in common? Near misses followed by successes.

Michael missed more than 9000 shots in his career. He lost almost 300 games. Twenty-six times, he was trusted to take the game winning shot and fell short. Yet, he never stopped working to perfect his skills and become the greatest athlete on earth...save Tom Brady

In the same way, the outcome of CF gene therapies in clinical studies conducted in the mid 1990s-early 2000s fell short. However, the CFF didn't simply go on a 15 year hiatus. Rather, over the past decade+, they have developed critical tools and acquired valuable knowledge related to CF gene therapy that has paved the way for gene therapy to reenter the playing field now.

Gene Therapy is not an easy concept to understand. Particularly when most of the information is embedded in scientific journals not found on the racks of your local grocery check out line. For that reason I invite you to review the attached flyers and watch this youtube video as a starting point to your journey on understanding how the CFF is working toward leaving no person behind in their mission to Cure CF.

Emily's Entourage: [Gene Therapy Town Hall](#)

(EE) Emily's Entourage (named after its founder, Emily, a 38 yo, smart, passionate, and doggedly determined woman with rare CF mutations). EE is a non-profit organization dedicated to educating the CF community (by holding informational town halls with learned CF scholars and doctors geared to the lay CF community at large) and fast-tracking research and drug development for rare, nonsense mutations of CF.

CF is a complex disease and thus developing gene therapies for it will involve challenges and setbacks. However, the CF community is continually developing resources and has the talent to tackle these challenges to ensure success. Please feel free to dialogue with your CF Care team about gene therapy.

research update
research update
research update

MOVE-A-PALOOZA

(Formally known as Walkorama!)

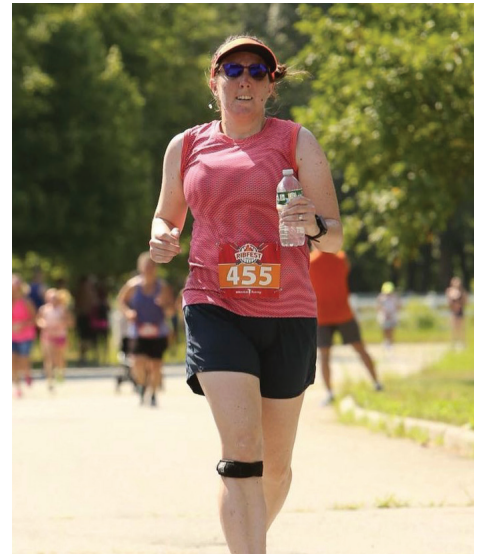


We are back and we want to get moving. It doesn't matter how fit you are! Last year 100% of our Walkorama participants said that they would participate again in 2024. We have decided to change our name to Move-a-palooza and be more inclusive...yes, all activity counts! You will record your activity minutes—yoga, walking, weightlifting, jogging, doing housework, it all counts!

Thank you to our Ambassadors Josh, Kerri and Danielle!

Here's what you need to know:

- Open to CF patients, their families and caregivers, CF Team or anyone connected with the Dartmouth Health CF Center.
- Register today (link and QR Code below!). Record your activity and report it weekly—we will be using the honor system!
- Move-a-palooza '24 will start on March 17 and end on May 5. Each week will have a theme—St. Patrick's Day, Spring, April showers, April Fools, Tax Day, Marathon Monday, Cinco De Mayo
- Stay tuned for prize details. Each participant will receive a Beanie hat and be entered in a draw for prizes. Best prize of all...we will be active!



Ideas!

- Walk in your neighborhood
- Deals at Gym—check new year offers or new member deals!
- Check your Health Insurance, some plans offer discounts in gyms.
- Check out your local recreation department for classes and events.
- Beam CF—[free online yoga](#)
- State parks or local trails – check out All Trails App.
- Your favorite hobby – weight training, walking your dog, skiing, biking

[Here are some more ideas from CFF](#)

Register here or scan the code



CF Registry

by Julia West

Many patients at our NH CF Center and other accredited CF Centers in the US participate in the CF Foundation Registry. The Registry is a longitudinal observational study of health outcomes such as lung function, respiratory infections and GI health, that includes information about clinic and hospital visits, use of different CF medical treatments, and rates of screening for complications of CF. Each year our NH Center receives information from the CF Foundation Registry about the health of our patients compared with previous years and compared with other CF Centers. This information helps us understand the health of patients living with CF in NH, what treatments are working well for our patients, and helps us identify areas of opportunity for continued improvement in CF care at our center. Last year the Registry data showed that we could do a better job of screening adult patients for CF-related diabetes, so our quality improvement team developed a project to improve our CF-related diabetes screening process. Patient participation in the registry is a great way to help our Center and the CF Foundation continue to understand and improve your CF care.

Molly's Corner

Some words of wisdom from Molly Stark MSW, our CF Social Worker in Manchester.

It's 2024 and I hope that this year has been treating you kindly so far!

The start of the new year offers us the symbolism of a fresh beginning, bringing with it the tradition of making "New Year's Resolutions." I don't know if you can relate, but in the past, my approach to this has been to make a long and ambitious list of goals which, by say mid-January, sadly end up forgotten. This year, however, I am going about this idea of "resolutions" with a different outlook, and wanted to share it with you. It is thanks to a book about the impact of tiny changes and consistent habits called *Atomic Habits* by James Clear, which I highly recommend!



One of the arguments James Clear makes is that when attempting to change habits, instead of focusing on the actual accomplishments you want to achieve, you might be better off first determining who you want to be. He writes, "every action you take is a vote for the type of person you wish to become." By naming attributes that you would like to have as part of your identity, you may find that your actions start to more naturally align with these identity statements.

For example, I have always set goals for reading more. I begin many a January saying "I will read 10 minutes a day" or "I will read 12 books this year" and each time, I get frustrated with myself that I neglect my goal. This year, instead of setting a specific goal, I have instead started telling myself, "I am a reader" and reinforcing this attribute as part of my identity. Once I start calling myself a reader, I must read—because what do readers do? They read! It seems silly or too basic perhaps, but for some reason, taking steps to solidify the claims I make about myself has worked for me, and I wonder if it might work for you too! Clear advises to take these steps:

1. Decide the type of person you want to be.
2. Prove it to yourself with small wins

Who do you want to be? A reader as well? An artist? A musician? A hiker? See what happens when you start to call yourself that which you hope to become. Clear states "The most practical way to change who you are is to change what you do."

This new year, try to leave the long resolution list behind, and instead focus on determining what identity you want for yourself, and find ways to demonstrate that to be true in your everyday life.

Snacks for Super Bowl Sunday

Buffalo Cauliflower Baked Mac and Cheese

Ingredients

7 tablespoons unsalted butter, plus more for the dish

Kosher salt

1 medium head cauliflower, cut into florets (about 4 cups)

1 pound elbow macaroni

2 stalks celery, finely chopped

1 small onion, finely chopped

2 cloves garlic, minced

3/4 cup hot sauce, plus more for serving, preferably Frank's RedHot

2 tablespoons all-purpose flour

2 teaspoons dry mustard

2 1/2 cups half-and-half

1 pound sharp yellow Cheddar, cut into 1/2-inch cubes (about 3 1/2 cups)

8 ounces pepper jack cheese, shredded (about 2 cups)

2/3 cup sour cream

1 cup panko

1/2 cup crumbled blue cheese

2 tablespoons chopped fresh parsley

Directions

1. Preheat the oven to 350 degrees F and butter a 13-by-9-inch baking dish.
2. Bring a large pot of salted water to a boil and fill a large bowl with ice water. Cook the cauliflower until just tender, about 5 minutes. Use a slotted spoon or spider to remove the cauliflower and immediately submerge it in the ice water to cool completely, then drain. Bring the salted water back to a boil and cook the pasta until al dente, about 7 minutes. Drain and set aside.
3. Meanwhile, melt 3 tablespoons butter in a large skillet over medium heat. Add the celery and onion and cook until soft, about 5 minutes. Stir in the blanched cauliflower and garlic and cook 2 minutes, then add 1/2 cup hot sauce and simmer until slightly thickened, about 1 minute more.
4. Melt 2 tablespoons butter in a medium saucepan over medium heat. Whisk in the flour and mustard until smooth. Whisk in the half-and-half, then add the remaining 1/4 cup hot sauce and stir until thick, about 2 minutes. Whisk in the Cheddar and pepper jack cheeses, then whisk in the sour cream until smooth.
5. Spread half of the macaroni in the prepared baking dish and pour over about half of the cheese sauce. Top with the cauliflower mixture and the remaining macaroni. Pour the remaining cheese sauce evenly on top.
6. Put the remaining 2 tablespoons butter in a medium microwave-safe bowl and microwave until melted, about 30 seconds. Stir in the panko, blue cheese and parsley. Sprinkle over the macaroni and bake until bubbly, 30 to 40 minutes. Let cool 10 minutes, then serve with additional hot sauce on the side.

[View full recipe here](#)



PLUS—[50 More Easy Snacks for the Big Game](#)

CF Foundation Northern New England Chapter News

Needed: Congressional Captain NH District 1

What is a Congressional Captain? A congressional captain is a volunteer advocacy leader who will work together with advocacy co-chairs, Sarah and Tim, and CFF staff to advance the foundation's policy priorities and help grow the network of advocates in NH District One.

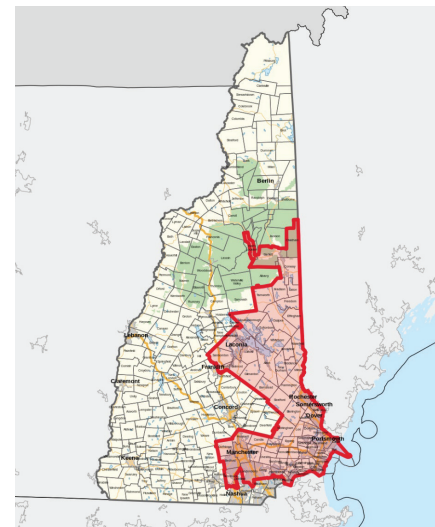
Who can fill this Captain's role? Anyone over the age of 18? Living in NH district one

What's expected from a Congressional Captain?

1. Stay up-to-date on CFF policy priorities with support from the CFF policy and government affairs team, NNE co-chairs, Sarah and Tim, and other captains in our NNE chapter.
2. Represent the CF community as you tell your CF story (Why do you advocate?) and build a relationship with your member of Congress and their team (particularly your House Rep office).
3. Help find, encourage, and educate others in your district to advocate.

Ready to start or have additional questions?

Contact Lisa O'Connor at loconnor@cff.org



BreatheCon

Calling Adults with CF, registration for BreatheCon is now open!

On Feb 9-10, 2024, the Cystic Fibrosis Foundation will host BreatheCon, a unique event to virtually gather with other adults with CF in a welcoming, inclusive space where you can be your authentic self

▶ [Register and learn more](#)

ResearchCon

On April 30 – May 1, 2024, the Cystic Fibrosis Foundation will host ResearchCon for everyone with a personal or professional connection to cystic fibrosis to learn and discuss CF-related science and care alongside others living with and studying the disease.

▶ [Learn more](#)

LOOK WHAT'S HAPPENING IN 2024!

Feb 1, 2024 NNE Volunteer Appreciation Night

March 8, 9 & 10, 2024 Ski for the Cure

May 5, 2024 Hanover Great Strides

May 18, 2024 Great Strides

Lancaster

Portland

Bangor

Augusta

Wolfeboro

Rutland

Nashua

July 13, 2024 Seacoast Safari CF Cycle for Life

September 14, 2024 Bar Harbor Great Strides

September 15, 2024 Burlington VT Great Strides

September 21, 2024 Belfast Great Strides



CYSTIC FIBROSIS

Patient & Family
Advisory Council
DHMC CF Center



Important Dates 2024

PFAC Meetings

Mon Jan 8th - 7pm

Tues Mar 5th - 7pm

Mon May 6th - 7pm

Tues Sept 10th - 7pm

Mon Nov 4th - 7pm

Transitions Group Meetings.

Tues Feb 6th - 7pm

Tues April 2nd - 7pm

Tues Aug 6th - 7pm

Tues Oct 1st - 7pm

Tues Dec 3rd - 7pm

AGM TBD

NACFC 24, will be held in Boston,
September 26-28 2024.