# CYSTIC FIBROSIS Patient Family Advisory Council



#### Holiday **Issue 2021**

The DHMC CF Patient and Family Advisory Council is a group of patients and families who live with cystic fibrosis, and members of the CF care team. We meet virtually every two months, and collaborate on projects that will enhance CF care.

#### **Our Mission**

The DHMC CF Patient and Family Advisory Council seeks to enhance the care and quality of life of the CF population. The 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 us at nhcfpatientfam@gmail.com if you are interested in being part of this group.

Newsletter team: Emily K. Dutille, Roni I. Finkelstein, Paula Garvey, Rosie Garvey, Kristin McCarthy, Ashlee Robinson, Jennifer Stover and Sarah Vooris,

#### What's inside?

**CF Community News** 

A note from Gunnar Esiason

An interview with Lisa Samuelson

**CF** Retreat Recap

What to expect when admitted

and much more





## **CF Community News**

Tilly is delighted to get a new tree house!









## Kerri Completes the Boston Marathon!

Well done Kerri!

Here are her thoughts from that amazing day!

The marathon was amazing! I really enjoyed being part of the CF team and was so happy to finish! My hip bothered me a bit the second half of the race so I didn't quite make my time goal but that's okay. I saw my fam at mile 20 and Dr Lapey—he's been a CF doc at MGH for 50 years and I did the Kalydeco trial with him—so it was a big pick me up for the finish. I hope to run again someday!



## Hannah is heading to Nationals!!!

Congrats to Hannah and the Merrimack Hawks
Varsity Cheerleading Team! They won the level 4 Pop
Warner Regional Competition and are now heading
to Florida to compete in the National Championships
at Universal Studios! Hannah started Cheer in 2015,
this is her 7th season and 4th time making it to
Nationals!!! Best of luck to Hannah and her team!





## Research Opportunities

#### A note from Gunnar!

I want to let everyone know about a couple pretty cool research opportunities that can be done remotely!

**First**, the CF Foundation is pioneering a real world evidence study that uses home reported outcomes that is entirely app-based! The study launched by Indiana University will ask people with CF and their families to track what they observe over the course of CF care while on Trikafta. The entire study is done from home using an app called Folia, which otherwise enables people to track their health. This is a novel kind of study that marries technology with everyday life. You can learn more here: **hero2study.com** 

**Second**, Thomas Jefferson University is conducting a pilot study of Acceptance and Commitment Therapy (ACT) with CF for adolescents aged 14–18. This is a telehealth pilot, so it is open to adolescents regardless of geographic location. Anyone who participates receives six sessions of Acceptance and Commitment Therapy specifically designed for adolescents with CF who have symptoms of anxiety and/or depression. If you think you would be interested please contact Chelsi Nurse at chelsi.nurse@jefferson.edu.

Thomas Jefferson University is also running a randomized trial for adults with cystic fibrosis to compare Acceptance and Commitment Therapy (ACT) vs traditional talk therapy. This is also a telehealth study, so it is open to you regardless of geographic location. If interested please contact Chelsi Nurse at chelsi.nurse@jefferson.edu.

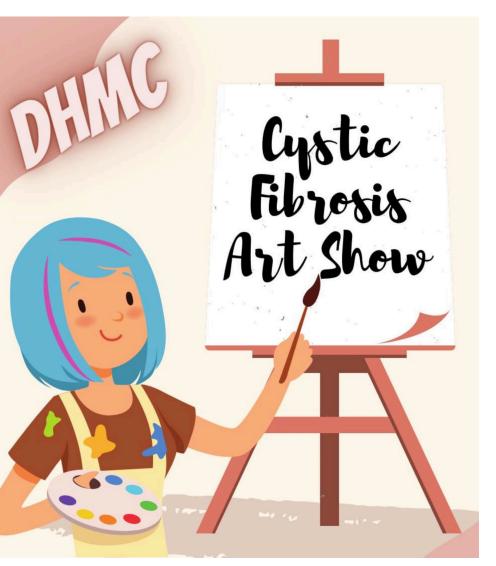
Gunnar Esiason



## CF Center News

### Artists wanted!

Submit your art to the First Cystic Fibrosis art show at Dartmouth-Hitchcock!



#### What

Art show for patients and family members affected by Cystic Fibrosis at DHMC in Lebanon

#### When

Artwork due by December 31, 2021 In person art show in Jan–Feb 2022

#### Who

Patients of all ages who have CF and their family members

#### How

Email Torie from Child Life victoria.miele@hitchcock.org to set up artwork submission. Can be either original art work (preferred) or high quality digital copy. Artwork can be brought into appointments, mailed, or emailed.

#### Why

To display the hidden talents of CF patients and family members

#### **Details**

Artwork must have a title or include a small blurb about the art

Artwork can be submitted anonymously or with first name and age of patient

Artwork can be returned to artist after show

Digital images to be used on online art gallery

Artwork can be about any topic or form, but must not contain inappropriate images or themes Reach out to Torie from Child Life 603-650-0226 or victoria.miele@hitchcock.org for more info



## Congratulations to Dana Dorman!

Research nurse, Dana Dorman, was awarded The Judy Williams Award for Research Coordinator Excellence at the CF Foundation Therapeutics and Development Network for her outstanding work at DHMC Manchester. For everyone who has participated in a research study, you know how passionate Dana is and so deserves to be recognized. Congrats Dana! And, if you need any information on research opportunities please connect with your CF team!

## Mindfulness and Self Care

#### **Gratitude Reflection**

Reflection is an important part of mindfulness meditation and the cultivation of a sense of self-awareness. These practices can lead to an enhanced sense of wellbeing, among other benefits, although enhanced wellbeing is enough of a benefit for most of us.

#### To practice gratitude reflection, follow these steps:

- 1. Settle yourself in a relaxed posture. Take a few deep, calming breaths to relax and center. Let your awareness move to your immediate environment: all the things you can smell, taste, touch, see, hear. Say to yourself: "For this, I am grateful."
- 2. Next, bring to mind those people in your life to whom you are close: your friends, family, partner... Say to yourself, "For this, I am grateful."
- **3.** Next, turn your attention onto yourself: you are a unique individual, with imagination, the ability to communicate, to learn from the past and plan for the future, to overcome any pain you may be experiencing. Say to yourself: "For this, I am grateful."
- **4.** Finally, rest in the realization that life is a precious gift. That you have been born into a period of immense prosperity, that you have the gift of health, culture, and access to spiritual teachings. Say to yourself: "For this, I am grateful." (Still Mind, 2014)

#### Positivepsychology.com

#### Mental health update:

Hi! I'm Roni, the new Social Worker based in Lebanon. I'm also the center's mental health coordinator, and am focused on increasing access to mental health for all CFers and their families. If you or anyone in your family is looking for a mental health provider and has had difficulty finding one, please reach out to me directly and we'll work together to find suitable care.

## Spotlight on Lisa Samuelson

#### **Adult with Cystic Fibrosis**

#### By Sarah Vooris

Our bodies are made to move. There are benefits of regular exercise and staying fit for everyone. For people with cystic fibrosis it can help with overall health, better lung function and more. As a child and into adulthood, Lisa Samuelson was always active. Swimming, competitive cycling, hiking and walking were favorites. But it wasn't until the age of 43 that Lisa discovered that these activities were also helping her body deal with cystic fibrosis, the disease that up until that point remained undiagnosed.

As Lisa dealt with lung infections and other respiratory issues while growing up, she continued to pursue her goals both athletically and educationally.



The majority of people diagnosed with cystic fibrosis are less than two years old. Born prior to newborn screening for CF and the Identification of the CF gene (CFTR) that has about 1,700 mutations, Lisa spent many years grappling with the symptoms of the disease without knowing their cause. "I had problems and issues, but CF never came up. I was in sports a lot growing up, swimming especially. I had some indirect physiotherapy without knowing it." Sinus infections, allergies, asthma, and shots for symptoms were common during this time of her life. "I didn't have typical GI issues as I am pancreatic sufficient."

As Lisa dealt with lung infections and other respiratory issues while growing up, she continued to pursue her goals both athletically and educationally. Starting out as a premed student, Lisa pivoted to a career in forestry, obtaining bachelors and masters of science degrees at the University of Georgia and a PhD from Virginia Tech. Postdoctoral work on air pollution and its impact on trees at the Tennessee Valley Authority and a professorship at Auburn University followed. Her career path has been a highlight of her life so far, "I picked the career I like. I love woods and forests, being outside, the biology aspect of it all. It wasn't necessarily





### Lightning Round

Swimming or rock climbing? Swimming

White birch or red maple? White birch

Pears or apples? Apples

Moose or black bears? Moose

Fall or spring? Fall

**Evergreens or deciduous?** Evergreen

Mac and cheese or Sushi? Mac and cheese

Coffee or tea? Coffee

lucrative, but it's been enjoyable." Forest ecology research, publishing three books about trees, and leading educational hikes and camping trips were also key parts of Lisa's career.

Over time, increasingly severe symptoms of CF developed and Lisa needed to know why. "I had a lot of pneumonia and didn't recover. I also had a partial lung collapse. I was referred to a good pulmonologist who asked about CF. My sweat chloride level was borderline and CF was confirmed genetically. CF was also confirmed with a nasal potential difference test." Now approaching sixty years of age, Lisa reflected on the wide array of emotions she experienced upon diagnosis. "Being diagnosed so late in life, it's a challenge. My parents felt quilty about it and I needed to explain genetics. I also considered: Do I need to change things in my life? What does this mean for the future? Different things with finances? Retire early? What does this mean for everyone I love? Should I tell my boss? Will people discriminate—intentionally or not?" Lisa was able to work with a therapist to navigate through her fears and questions, deliberating over what was within her control and what was not.

Finally correctly diagnosed with cystic fibrosis, Lisa began CF treatment regimens. She began taking Trikafta in 2019 adding, "I take Trikafta and it's amazing. I don't cough anymore. I have clear sinuses, lung clearing and less mucus. I've gained weight, but in many cases that's a good thing. A miracle drug—at least it has been for me." Lisa also continues to find exercise a helpful supplement to her care. "Initially I feared that if I didn't get out and do it, I may slide. I like to exercise every day—hiking, walking. Sometimes I'm too tired, but I will do it tomorrow or the next day. I love to get outside and encourage others to find an exercise they love and do it."

With improvements in genetic testing, an increasing number of older people are being diagnosed with CF. Living years with misclassified symptoms and receiving a diagnosis later in life presents a unique set of challenges and another perspective.

Thank you, Lisa, for sharing your experience with us!

## CF Retreat

#### By Paula Garvey

Did you know that every year our DHMC CF Team takes time to meet to review their work from the past year and plan how to better care for the 212 CF patients in DHMC over the next year?

I was invited to attend the retreat this year as a PFAC member and a CF mom. I am always aware of the thoughtfulness, thoroughness and genuine passion that our CF team has, and this was so evident during retreat. It was a time to reflect and acknowledge what went well during the year, and discuss what improvements need to be made and how they can be implemented. Meeting in person was a little challenging, but so welcome—full COVID-19 protocols were followed so we made it work and enjoyed the fresh air at any given opportunity!

This past year was very different for our team, having to use telehealth and continue to work through a pandemic, but it is reassuring to know that the team adapted as needed and care was never compromised. It was a great opportunity to catch up and discuss issues during the planned discussions and outside of the agenda. Patients who are no longer with us were remembered. We welcomed our new social worker, Roni Finkelstein, and met our new CF Pedi Doctor, Scott Schroeder, who will join us in November and remembered fondly the members who had left the team this year. There was also time to catch up, go for a walk, or even a swim at lunch time!











## CF Retreat

## There was a full, comprehensive agenda, here are some of the topics that were discussed

- Improving transition to adult care
- Developing an Inpatient Handbook for both Pedi and Adult
- CF registry data from the past year (see the article in the newsletter and family night)
- CF Related Diabetes
- CF research update and discussion
- Plans for dealing with Covid-19 cases
- Mental health screening
- Pharmacy updates
- Clinical pearls of CFTR Modulators (Trikafta, Symdeko, Orkambi and Kalydeco)
- Gl issues, such as Vitamin D levels and disordered eating in CF patients
- Child-life: goals for the year and MIND BLOWN, our CF educational project
- PFT's and Home PFT's
- CF Patient resources: Compass and Karen's Climb
- Family night November 17th
- North American Cystic Fibrosis Conference November 2–5

And of course, a comprehensive "To-Do" list, working on items such as a fast pass for CF Patients for admission, updating the website, access to insulin for inpatients, the very important topic of scheduling clinic for the next year

and lots more! It was a very busy couple of days, but very productive, it is so reassuring to know the time and organization that goes in to making sure that our CF patients and families have the best possible care. Our team strives to follow their Mission Statement always. Thank you so much to our AMAZING team!









#### **Mission Statement**

The New Hampshire Cystic Fibrosis Center's mission is to provide compassionate, responsive, collaborative care and support in partnership with people and their families affected by cystic fibrosis. Our team promises to create an environment that promotes long-term education and empowerment of the individual in an atmosphere of hope. We will continuously improve our quality of care through innovation, advocacy and an evidence based approach including research and consistent application of best practice. Our ultimate goal is to optimize patient outcomes, quality of life, and well-being.

## MindBlown Kit Update

By Sarah Vooris and Torie Miele

"MindBlown: The Ins and Outs of Cystic Fibrosis" are educational kits designed for learning about CF. MindBlown kits provide a fun and engaging way to explore how cystic fibrosis affects the body and how treatments help people with CF stay as healthy as possible.

Designed for children between the ages of eight and thirteen and their caregivers, MindBlown kits include hands-on activities to teach about specific body systems and the impact of cystic fibrosis on these systems. Kits explore the strategies available to address CF specific changes in the body, such as the role of digestive enzymes to break down and absorb nutrients. Each kit contains items necessary for completion of the projects included. The first set of kits focused on the respiratory system. These kits have been completed by many kids with CF. In addition, kits have been given to siblings of children with CF and children whose parents have the disease. Over 50 kits have been shared from the Lebanon and Manchester clinics.

A key partnership with the New Hampshire CF Center supplied grant funding for the first MindBlown kits. We have obtained additional grant support from the Boomer Esiason Foundation. A grant of \$4,000 from the BEF helps cover the cost to complete the next two kits. Increased funding also allows for the inclusion of a relevant book to match each body system and a prize for participants after completion of kits. Thank you to the Boomer Esiason Foundation for helping us to move forward with more kits! The next set of kits explores the gastrointestinal (GI) system.

Distribution of MindBlown kits is coordinated through the CF clinic with ongoing collaboration between the CF team and kit participants. Please contact your child life specialist: Torie Miele or Sonya Charles. Kits can be completed at home, done with child life specialists during CF clinic visits or while admitted as an inpatient. The effectiveness of each kit will be checked using tools such as surveys and interviews. We look forward to getting you and your child's feedback. As partners we can assess how well the kits are working, understand what is effective and what can be improved. Your feedback also helps us as we work to develop future kits.

#### Here's what kids are saying about MindBlown Kits:

"There's a lot of information packed into each kit. I liked to do the kits one activity at a time, piece by piece, instead of all at once. I learned some new things." PT (13 yo)

"I learned about spreading germs. The kits are a lot like the kiwi crates I get. They are fun and help me learn about my body and stuff." PT(7yo)

"I liked the activity of blasting the germs all over the room.

I learned germs travel when we cough, but not when you wear your mask." PT (10yo)

"I like making the slime because it was a lot like my sticky mucus." PT (12yo)

If you would like to add helpful feedback about the kits, check out our short survey: https://www.surveymonkey.com/r/SZW3YZ9 or reach out to your child life specialist!



## What to expect when admitted



#### Adult with CF:

To get your favorite foods, ask the dietitian for help! They know where all the good snacks are hiding and how to get them to you. Also make sure you ask for a mini fridge in your room so you can bring in food from home.

To avoid delays in treatment and extra cost, bring your own meds and equipment (enzymes, vest, etc). Depending on what enzymes you take, pharmacy may not have them in stock and it takes a while to get the dose adjusted and a bottle to your room. Your life will be so much easier with your own vest/settings too!

Give your nurse your cell phone number so you can leave the floor for walks, lunch outside in the sun, etc. Coordinate with the nurse so you know when your next med dose is due. Then you can go off the unit and they can reach you quickly if you need to come back!

Keep a hospital bag packed and tucked in the closet in your house. Bring it with you to clinic visits if you think you might get admitted. I keep travel-sized shampoo, conditioner, etc, a comfy set of clothes, a cozy blanket, flip flops, headphones and an extra phone charger. This way if I get admitted, I always have enough to get me through at least one day until someone can bring me more stuff from home.

## Highlights of the Virtual NACFC

This years North American CF Conference took place from November 2–5. Unfortunately, due to Covid 19, it was virtual, however, due to it being virtual it meant that more people had access to participate. Many presentations were recorded and will be available to watch. Here are some takeaways from our CF Team:

- The introduction of highly effective modulators has impacted all people with CF, whether or not they are eligible to take them. As the Mental Health Coordinator, NACFC highlighted how important it is to screen folks for mental health needs regardless of their physical health status."
- It is such a time of hope, I am eagerly following research on gene editing. Also, I was fascinated with the need to change diet when on modulators—big change from previous guidelines! Briefly, there is increased fat absorption so potential for weight gain, think 'healthy fats' (fruit and veg based), decreased salt needs, decrease animal fats and sugars. Overall, a general healthy diet such as the Mediterranean diet is beneficial."
- My take away is more of an observation related to the number of life events many CF'ers are now experiencing. Due to the increase in life expectancy, many are now doing things they previously did not expect to. Very exciting."
- Data suggests that patients and caregivers find it beneficial to have a pharmacist in-clinic as a core member of the care team"

A highlight for me at NACFC was the work being done to address Food Insecurity and Health Equity in CF Care. The session on equity was part of the complimentary track S01U&C-CLIN: *Health Equity in CF Care. We still have work to do to ensure ALL people with CF have what they need to take care of their health."
Take-away from NACFC: How many mind-blowingly BRILLIANT people are working together to solve this entity called CF."
My takeaway is that even with highly effective modulator therapy for the majority of patients the CFF is truly not stopping to have those treatments for 100% of patients AND to go past that to get to a cure!"
I walked away from NACFC with a goal to have 80% compliance with home spirometry before a clinic appointment by March of 2022. And 100% compliance August 2022. Because I attended numerous presentations demonstrating that it's feasible."
I was impressed with the brilliant people working on innovative ways to solve the puzzle of CF. There are amazing new therapies being developed to truly cure CF at a molecular level. Truly inspiring."
NACFC takeaway: celebrating the increased age/life expectancyit's just going to keep on getting better!"
My takeaway is that we are not done finding breakthroughs and new discoveries in CF!"

### Karen's Climb

#### About Karen's Climb:

Karen Larlee Grant died of cystic fibrosis in December 1984. As a teenager Karen overcame extreme physical odds in climbing Maine's Mt. Katahdin despite having a debilitating and live-limiting respiratory illness. Her courage and determination in making that climb lives on through the "Karen's Climb" Foundation.

Karen's Climb funds are provided to local people with CF and/or their families to help with a financial issue directly related to cystic fibrosis



### Please support Karen's Climb!

If you would like to help local CF patients and families in this season of giving, please consider donating to Karen's Climb. This fund provides help for local CF patients and families in need.

Checks can be made payable to **The Hitchcock Foundation**, with **Karen's Climb** in the memo, given to the CF team during your next clinic visit or mailed to:

The Hitchcock Foundation One Medical Center Drive Lebanon, NH 03756

Donate online here, noting "Karen's Climb" in the "name of the fund" field:

dartmouth-hitchcock.org/hitchcock-foundation/donate-now



## Recipes

#### Tortellini Tomato Spinach Soup

#### Ingredients

1 tablespoon olive oil 1 cup chopped onion





1 (14 ounce) can diced tomatoes 1 package of tortellini

10 ounces chopped frozen spinach, defrosted

freshly grated parmesan cheese (optional) Salt and pepper to taste

#### **Directions**

In a medium pot, heat olive oil over medium high heat.

Saute the onion and garlic, stirring often until onions are translucent, about 5 to 7 minutes. Add broth and tomatoes, turn heat up to high, and bring to a boil.

Add the tortellini and cook according to package instructions.

When tortellini is almost done, add spinach and taste, adjusting seasonings with salt and pepper.

Serve immediately. Garnish each serving with a sprinkling of parmesan



This is a favorite for Fall lunches in the Garvey household and is so simple to make! I use my immersion blender to blend and add a little cream too!

#### Ingredients

1 large butternut squash, peeled and cubed (seeds removed)

2 potatoes, peeled and chopped

3 tbsp. extra-virgin olive oil

Kosher salt

Freshly ground black pepper

1 tbsp. butter

1 onion, chopped

1 stalk celery, thinly sliced

1 large carrot, chopped

1 tbsp. fresh thyme or parsley, plus more for garnish

1 qt. low-sodium chicken or vegetable broth



Preheat oven to 400°.

On a large baking sheet, toss butternut squash and potatoes with 2 tablespoons olive oil and season generously with salt and pepper. Roast until tender, 25 minutes.

Meanwhile, in a large pot over medium heat, melt butter and remaining tablespoon olive oil. Add onion, celery, and carrot and cook until softened, 7 to 10 minutes. Season generously with salt, pepper, and thyme.

Add roasted squash and potatoes and pour over chicken broth. Simmer 10 minutes, then using an immersion blender, blend soup until creamy. (Alternately, carefully transfer batches of the hot soup to a blender.)

Garnish with thyme or parsley, and a little grated nutmeg if desired.

Nutrition (per serving): 369 calories, 10 g protein, 55 g carbohydrates, 8 g fiber, 9 g sugar, 15 g fat, 4 g saturated fat, 491 mg sodium

#### Chocolate Chippy Yogurt

CF kid approved recipe that is easy, high protein and high fat. It's called "chocolate chippy yogurt" at our house and tastes a bit like a peanut butter cup. 1-2 tbsp powdered peanut butter (PB fit is the brand we use)

1 cup or so of full fat vanilla yogurt

Mini chocolate chips

Mix the powdered peanut butter into the yogurt and sprinkle with chocolate chips.

Kristin McCarthy





Tomorrow's Leaders is the Cystic Fibrosis Foundation's Young Professional program. This dedicated group of adults, ages 21+, is committed to finding a cure for cystic fibrosis, while growing personally and professionally.

Tomorrow's Leaders have opportunities on both the local and national level to meet other young professionals both locally and from across the country. In addition to opportunities to connect, Tomorrow's Leaders also have the opportunity to partake in nationwide personal and professional development tracks.

As a Tomorrow's Leaders you have the chance to make a difference, raise awareness for cystic fibrosis and be a part of the generation that finds a cure!



To learn more about becoming a Tomorrow's Leaders
Member, or about joining the council, for the Northern New
England Chapter- reach out to Caitlin at cgoodhile@cff.org or
351-203-0953





#### WHAT IS TOMOTETEOW'S LEADETES?

Tomorrow's Leaders is the Cystic Fibrosis Foundation's Young Professional program. This dedicated group of adults, ages 21+, is committed to finding a cure for cystic fibrosis, while growing personally and professionally.

#### DOES IT COST TO JOIN?

Nope! There is absolutely no cost to join and there are no fees associated with joining.

#### WHAT DOES "JOINING" ACTUALLY MEAN?

Great question! As a Tomorrow's Leader you gain access to both local and national events. On the local level, you'll be invited to attend our events- whether it is virtual or in person! Even when we are back in person, we will still be able to have virtual options for people to join in virtually. There is no requirement to attend all of them.

## WHO ATZE THE "COUNCIL"? DO I HAVE TO BE ON THE "COUNCIL" IF I JOIN?

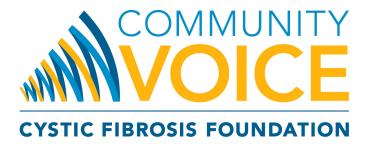
Our Tomorrow's Leaders Council Members are our Tomorrow's Leaders who plan our events. They work similar to a committee with planning events and recruiting more members. A Tomorrow's Leaders member is someone who is a part of our Tomorrow's Leaders group and is invited to attend our local and national events. If you join Tomorrow's Leaders, you do not have to be a council member!

Cystic Fibrosis Foundation Northern New England Chapter has moved!

New address:

Cystic Fibrosis Foundation Northern New England Chapter 20 Trafalgar Square, Suite 447 Nashua, NH 03063





#### What is Community Voice?

People living with cystic fibrosis and their families know CF better than anyone. Community Voice is an empowering volunteer opportunity for you to share your experiences and perspectives. As a member you can make an impact by bringing your insights and priorities to the forefront of CF research, care, and programs.

PARTNER with the CF Foundation, researchers, and other organizations.

research through exclusive updates.

the future for the entire CF community. Your participation makes a difference.

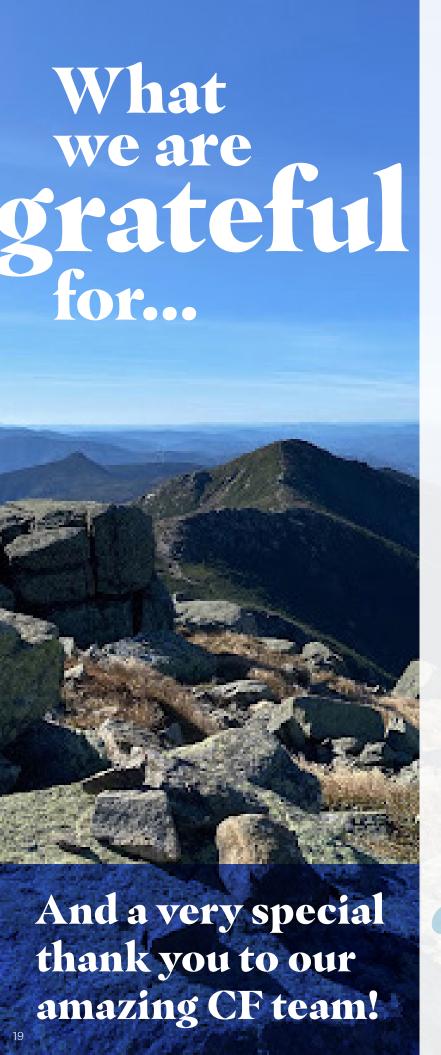
#### HOW IT WOTEKS

- Choose when and how often you participate - no minimum commitment required to be a member.
- Receive emails with tailored opportunities to participate based on your interests.
- Share your opinions through online surveys, focus groups, committees, and more.

"Community Voice makes me feel powerful. I'm a part of something more, which will make a difference for everyone in the community."

- Marieliz, Community Voice Member

Scan the code to join today, email communityvoice@cff.org, or visit: cff.org/CommunityVoice



I am grateful for science and medical innovation.

I am grateful for the loved ones in my life and what they have given me. I could not be who I am today without them.

I am thankful for coffee!

I am thankful to be surrounded by my family and friends and for Sunday dinners bringing us all together.

I am so grateful for my family and friends and the beautiful woods that I walk in.

I'm grateful to stand on mountain tops. It keeps everything in perspective.

I am grateful for the enthusiasm, creativity and talent of our own CF team here and the CF community at large.

I am grateful for access to COVID-19 vaccines for so many and boosters too!

Gratitude: To all the people with CF who have selflessly given time, energy, and even parts of themselves like blood and tissue samples to make the discovery of new therapies possible.

I am deeply grateful for a dedicated, compassionate and expert team of CF caregivers that I have the privilege to work with every day.

This is a wonderful day I've never seen this one before."

Maya Angelou