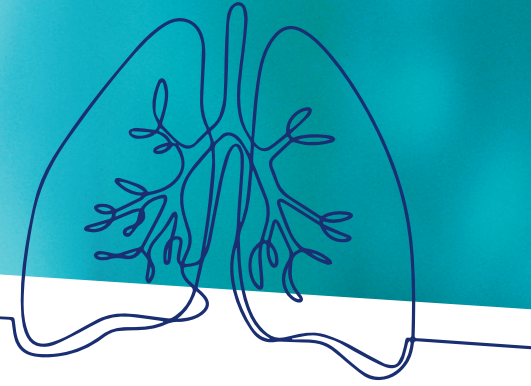


# CYSTIC FIBROSIS

## Patient & Family Advisory Council

DHMC CF Center



### Winter Issue 2022

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](mailto: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?

### A Focus on Health & Wellness

- CF Community News
- A Spotlight on Kerri Boucher
- Wellness Tips
- PFTs
- Dietary Recommendations  
in the Age of Modulators
- and much more

Follow  
Us





# CF Community News



## Thoughts on being part of a Clinical Trial

by Drew, an adult living with CF

“Trikafta has changed my life. I’m so grateful to feel so healthy and a sense of normal in this crazy CF life. Dana is also always making these studies so easy. I’m so glad to see the hard work pay off and I hope others feel the improvement in the quality of life as I have had. I am absolutely unstoppable now and it’s all thanks to the people who pour their hearts and souls into the research and development of these life changing drugs.”

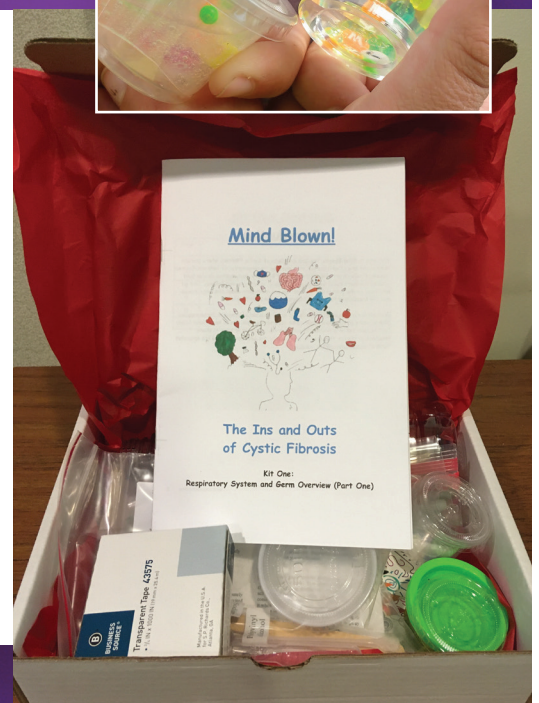
*For more information on participating in a clinical trial please contact your CF Team*

## Mind Blown Educational Kits!

The Boomer Esiason Foundation has accepted our proposal for funding for future “MindBlown! The Ins and Outs of CF activity Kits”!

With their help, we will continue to make kits to help kids six and up learn and understand the various pieces of CF. We are so thankful to partner with them and have our next kits on the GI system being assembled soon. Don’t forget to take a quick survey on the kits if you’ve completed them already: [www.surveymonkey.com/r/MKWD7RZ](http://www.surveymonkey.com/r/MKWD7RZ)

*For more information about MindBlown kits contact Torie, Child Life Specialist. Congrats to CF mom Sarah and Torie on making this happen!*





# CF Community News

Our CF team, patients and families are masked, vaxed, and boosted!



## Exciting News from the CF Foundation and Beam

The CF Foundation has renewed their agreement to provide free access for U.S. adults to Beam [[t.e2ma.net](https://t.e2ma.net)] through June 2022.

Beam Cystic Fibrosis is an online, physical activity and wellness platform designed specifically for people with CF. Adults 18 years and older can join live or on-demand classes on a variety of exercise styles and wellness techniques, including yoga, posture, dance, HIIT, and more. Beam also offers series classes targeted to individual needs, such as the "Trikafta Fit" and "Post-Transplant Embodiment." Interested patients can register online using the Get Started [[t.e2ma.net](https://t.e2ma.net)] button. No promo code or payment method is necessary.



Reid playing on the frozen pond behind his house



# CF Center News



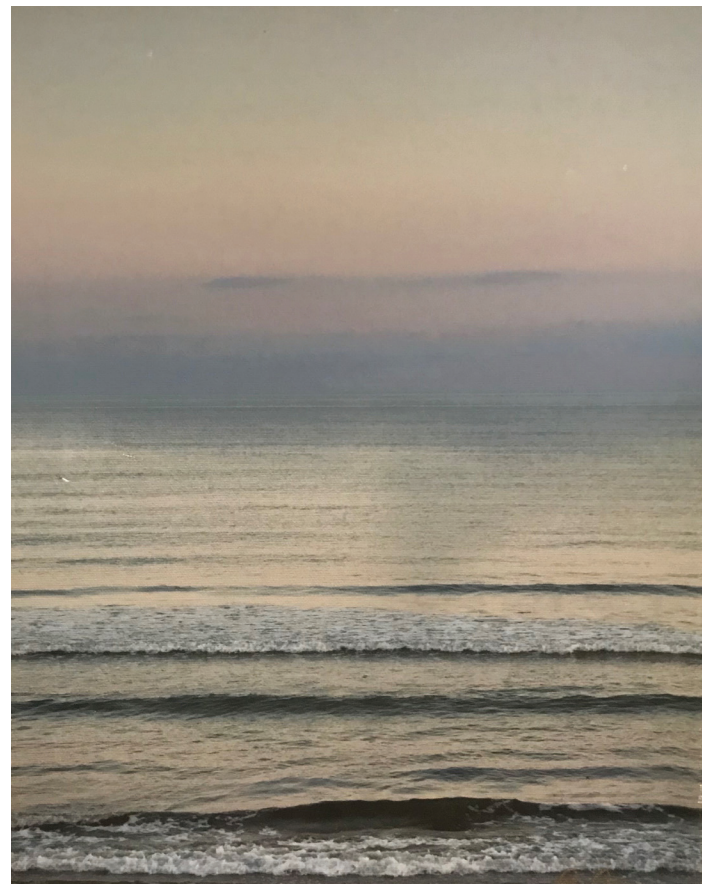
Our CF patient and family art show *The Art of Breathing* has been postponed until March 2022. For now, enjoy this sneak peek.

We are still accepting any type of artwork from patients and family members who want to show off their skills. It will be displayed at DHMC and be included in a virtual art show for all to enjoy.

Reach out to Torie, Child Life Specialist at [victoria.miele@hithcock.org](mailto:victoria.miele@hithcock.org) or 603-650-0226 to submit your artwork or with any questions.



*Purple Ribbon* by Danielle pediatric CF patient  
Medium: Band-aids and tempura



*No Horizon* by Rosie adult CF patient  
Medium: Photography



# CF Center News

## A note from Lynn!

A QUICK and IMPORTANT REMINDER for you all:

**FACT:** COVID Vaccines STOP severe illness, hospitalizations and death. It is never too late. We have had several COVID cases in our pediatric and adult CF population in the past few weeks and those who have been vaccinated have weathered the illness much better than the unvaccinated folks filling up our ICUs and hospital beds. So please take the step. And remember the CDC has authorized boosters for children ages 12–17 as long as it's been 5 months since their last shot.

Here are links to easy access to COVID vaccinations near you:

Sites in VT

Sites in NH

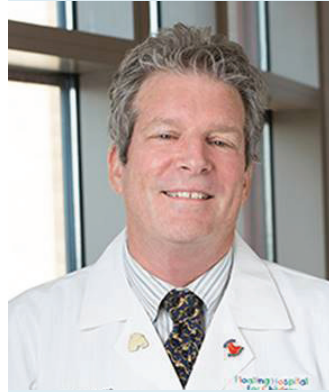
[vaccines.gov](https://www.vaccines.gov)

Finally folks – the government has made at home test kits available to everyone **FOR FREE**. Just click on this link and order now. Short of vaccinating and masking, testing if you are symptomatic is the best way to protect others should you be infected. Just follow the instructions on the kit carefully and know that the tests are best used if you have symptoms.

Free at-home COVID-19 tests:  
[COVIDtests.gov](https://www.covidtests.gov)

## Welcome Dr. Scott Schroeder!

Dr. Schroeder comes to us from Tufts Children's where he was Chief of Pediatric Pulmonology and Allergy. He decided he wanted to be a doctor



while in the Peace Corps on the island of Borneo; he shadowed a physician working and was hooked! Dr. Schroeder graduated from UMass Medical School in 1984 and completed his Internship, Residency, and Fellowship at Mass General Hospital for

Children. We're excited to have him join our team and get to know him! Welcome Dr. Schroeder!



## Dartmouth-Hitchcock Cystic Fibrosis Center Patients and Families Facebook Page

Please check out the DH Cystic Fibrosis Center Patients and Families facebook page. This private group is managed by the DHMC CF Center and is a great place to access the latest CF news!

[facebook.com/groups/DHCFCenter](https://facebook.com/groups/DHCFCenter)



# Cystic Fibrosis Foundation Patient Registry (CFFPR):

## Noticing Patterns to Learn and Change

by Sarah Vooris

**What is the CF Patient Registry (CFFPR)?** Since 1964, the CF community has gathered voluntary data on the health status and treatments from patients in accredited CF centers. Now known as the CFF Patient Registry (CFFPR), it is one tool used to increase understanding of the disease, improve care of people with CF, and ultimately find a cure. Patterns shown in the registry data have led to the creation of CF care guidelines, guided improvement plans at CF centers, inspired research and the design of clinical trials, and more. Today, the CF Registry is a model for other chronic illness disease patient registries, with more disease organizations and foundations realizing the benefit to this observational data over time.

**Who makes the CFFPR possible?** All individuals diagnosed with CF receiving care at accredited CF Foundation centers can participate in the CFFPR. It's voluntary. Parents/guardians provide consent for minors. At the age of 18, all patients are asked to decide for themselves as legal adults. All those agreeing to have their data collected have their names changed to patient numbers by the CF Foundation. This conversion ensures privacy of health information.

With patient consent, information on such things as lung function, genotype, microorganisms grown in cultures, medicines prescribed, hospitalizations, and growth patterns is collected. In fact, more than 300 pieces of data are added to the registry for each patient!

People with CF and their families who agree to share their data, CF care team members, the people who enter data into the registry, researchers, and members of the CF Foundation work together. It is this group effort that makes the CFFPR a successful means of observation and improvement of care for people with CF.

**What are CFFPR Reports?** Every year the CFF analyzes and produces reports based on current data. Each center receives their own report. In addition, the CFF also publishes a summary of the data's key findings. This summary highlights patterns in the data across the 130 CF centers in the US. It provides a big picture view of successes and areas in need of improvement.

The most recent data available from the CFFPR is from 2020 ([link below](#)). The major benefits of the registry come when we use it to find patterns over time. However, it is also important to recognize that there are limits to what the CFFPR data can tell us. 2020 is an example of this. The COVID-19 pandemic presented challenges and changes that show up in registry information. For example, the number of people getting bacterial cultures decreased nationwide due to fewer in person clinic visits.



**Why does the CFFPR matter?** Condensing the data collected via the CFFPR is a massive undertaking. For our CF center, the pediatric and adult reports are each 121 pages long for 2020 alone. This information is added to data from all other centers and to the wealth of data from years past. Trends found in the CFFPR have led to changes in care and have increased our knowledge of CF. Examples include, but are not limited to the following:

- Researchers use the registry to observe CF treatments and their real world results. This can lend itself to further and more rigorous research in clinical settings. For example, trends in what microorganisms grow in bacterial cultures influence the creation of new antibiotics and trials analyzing their safety and effectiveness. (e.g. [cff.org/news/2022-01/cf-foundation-awards-47m-enbiotix-inc-develop-inhaled-antibiotic-treat-pseudomonas](https://www.cff.org/news/2022-01/cf-foundation-awards-47m-enbiotix-inc-develop-inhaled-antibiotic-treat-pseudomonas))
- With the knowledge that people with CF are living longer, the need for adult programs was apparent. This helped lead to the creation of CF adult care programs with resources to support adults and their needs. Since 2014, registry data has been split into pediatric and adult groups enhancing the ability to notice trends in these diverse groups.
- Differences in treatment approaches at CF centers can show how well those treatments work. For example, in the past registry data observation showed that different nutritional approaches led to better growth and lung function. Guidelines for nutrition were developed. And with the use of modulators like Trikafta, the CFFPR has provided data leading to potential changes in nutritional guidelines. On this issue and others, centers collaborated to learn from one another to further progress CF care.
- Researchers, in collaboration with CF centers, use registry data to design CF clinical trials. Knowing the CF mutations of patients, centers can more quickly identify individuals willing and able to participate in trials for modulators. This is also why studies on modulators focused on certain genotypes first as these genotypes, or mutations, were shown as the most common in the registry. It is also how researchers know where to shift their focus next, on helping people with genotypes less common or rare using other methods (see: [cff.org/research-clinical-trials/path-cure-many-routes-one-mission](https://www.cff.org/research-clinical-trials/path-cure-many-routes-one-mission)).

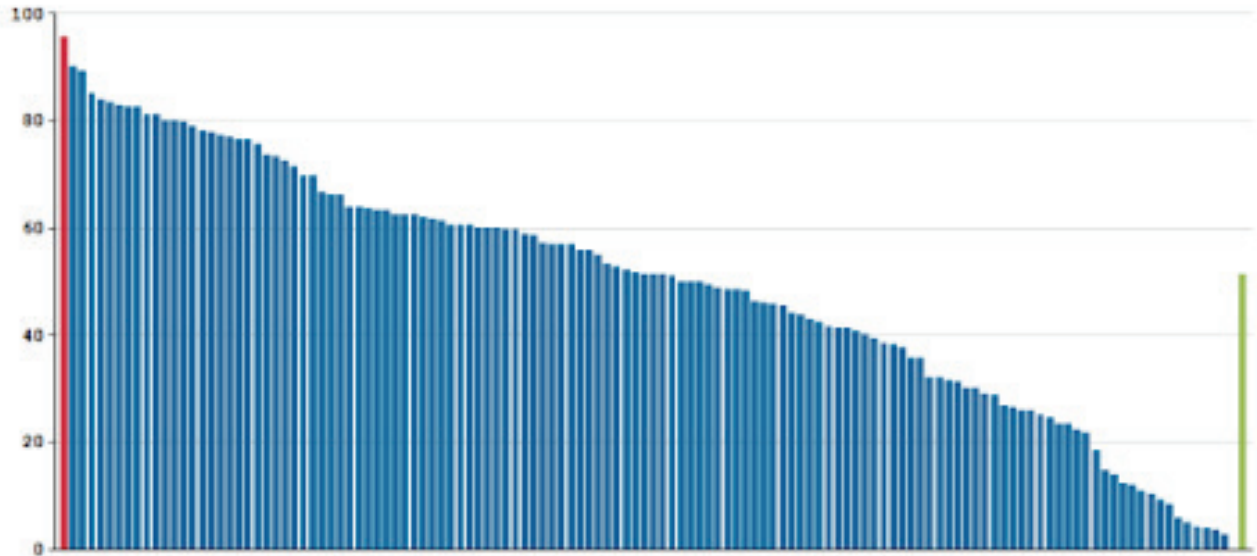
**How might the CFFPR help people with CF individually?** Many individuals with CF can pinpoint areas where changes brought about with the help of the CFFPR have been beneficial. It is important to highlight that data on the CFFPR is observational, it is not a study like a clinical trial - with blinded control and experimental groups. There are limitations. For example, the registry shows what respiratory treatments may be prescribed, but can't tell us how many people are actually using them on a daily basis. It can collect data on who counts exercise as airway clearance, but not what types of exercises those actually are. For that a conversation with the CF center team would be better.

Even with these limits, it is possible to look at registry information from our center and the nation from an individual point of view to learn and grow. For example as a parent of children with CF, I considered the following when reviewing the CFFPR data from 2020:



- Our center’s focus on getting pediatric patients assessed for diabetes using OGTT testing was the best in the country this past year! (see graph) This oral glucose tolerance testing helps to diagnose CF Related Diabetes. Early diagnosis and treatment of CFRD may lessen its impact. Knowing this makes it easier to encourage that list sip of super sweet beverage!

### OGTT Screening in Non-Diabetic Patients 10 Year and Older in 2020, by Program



Each bar on the graph represents a CF center. Our NH CF center is in red, with approximately 95% of eligible patients completing a screening test. The green bar is the average across the accredited centers nationally.

- Treatments are leading to changes in growth for people with CF. What does this look like for the food we eat at our house? What changes may need to happen? Thankfully, our center nutritionists and GI specialists are already on top of this issue.
- What is fecal elastase? Nationwide data showed the measurement of fecal elastase didn’t happen much across centers. But, this measurement provides an objective way to see how the pancreas is functioning. A BM sample to see how those enzymes are working? To see if the modulator is changing the GI system in a beneficial way? What could this mean for my daughter and how she takes enzymes?
- The registry has collected data on people with CF getting COVID-19. We can talk to the CF team or see the data to get a better idea of how people with CF handle the virus or on the effectiveness of vaccines.

### I have questions about the CFFPR.

#### Who should I talk to?

Please direct any questions to a member of your CF team.

#### Additional Information:

[cff.org/medical-professionals/patient-registry](https://cff.org/medical-professionals/patient-registry)

[cff.org/sites/default/files/2021-11/2020%20Annual%20Data%20Report.pdf](https://cff.org/sites/default/files/2021-11/2020%20Annual%20Data%20Report.pdf)



# Spotlight on Kerri Boucher

By Sarah Vooris

Every person is a puzzle. We have many pieces of ourselves that come together, forming a picture of who we are. Our relationships, interests, and circumstances are a few of these integral parts. Kerri Boucher is a daughter, sister to someone with CF, wife, college grad with a full-time job in finance, avid traveler, Harry Potter fan, active fundraiser, and runner. Kerri also has CF, a piece of her life's puzzle, essential to understanding the whole picture, but only one of many parts.

We had the privilege of getting to know Kerri via this issue's Spotlight Interview. Enjoy the following interview (edited for clarity) and thank you, Kerri!

## What was it like growing up with a sibling who also has CF?

We (Kerri and her sister) had a normal sibling relationship, but in regards to health, we could definitely relate to what each other was dealing with. We did know a few families that had kids with CF, but growing up it wasn't as easy to connect with others your own age with CF like it can be now with social media. So we had each other. We were able to talk about how we felt, challenges, and share stories about our CF. We still do.



*A pic from the CF walk in the early 90s. I'm the third girl from the left, my sister is the redhead by the letter C on the sign.*



*A finish line pic from a fall half marathon*

## Your parents were involved with fundraising for the CF Foundation. Did you get involved in fundraising events when you were younger? If so, how?

Yes, we grew up doing the CF walk (now Great Strides). We would walk with friends and family members each year, help with the set up, and hand out shirts. At the time, my parents would help organize the event and we would walk at Mines Falls in Nashua. We would then have a celebratory cookout at my parents' house.

I didn't tell many people that I had CF when I was younger. Sharing my story and fundraising has been



a bigger part of my adult life. Each year I try to do a race for a CF charity and fundraiser. We've run the Chicago Marathon, New York City Marathon, and Boston Marathon as part of CF charity teams (like Team Boomer, CF Center at MA General).

## Who in your life do you think has had the most influence on you? Why?

This is a tough question—I think it's a combination of people throughout my life. The biggest would be my parents who always supported us in our goals and did everything they could to help us reach them.

## Why did you join clinical trials?

My first clinical trial was the phase 3 trial of Kalydeco. At first I was nervous about doing it because I was in an okay place with my health but my CF doctor (Dr. Parker) told me that I was eligible with one of my gene types.

After talking about it with him and my family, I felt that I needed to do it - not only for myself, but for others. I think that by participating in trials, you are helping further research that may improve your health—even save your life—but it is also helping advance treatments for the CF community. Sometimes the med or treatment may not be approved or approved for your gene types which has happened to me, but it is still helping someone. Your time is never wasted.

## What inspired you to take up distance running?

After doing the Kalydeco trial, I wanted to do something that I had never been able to do before so I asked my husband if we could do a 5k. We did and had a really great time at the event so we kept doing several local events during the year. It grew to include longer distances and traveling to races. It's definitely a fun way to see the country while helping to maintain my health and lung function.

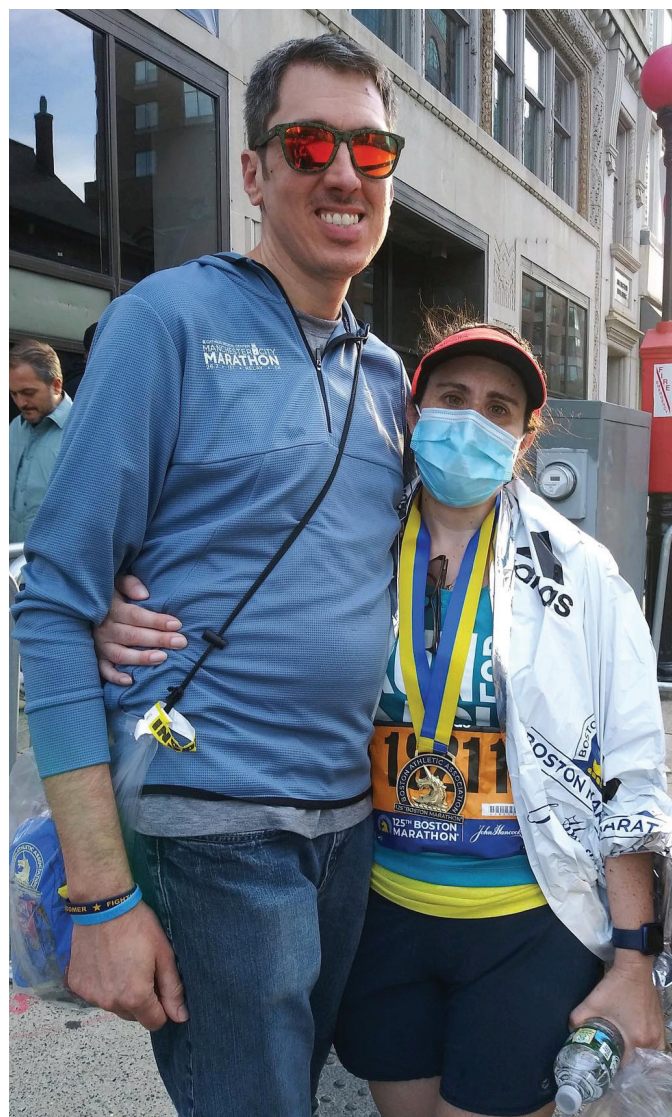
## What steps do you take to make things work? How do you navigate working full time, running, your CF care, and other parts of your life?

It's definitely challenging at times to get everything done. I have a great support system with my husband and my parents who have always been there for me especially when I wasn't feeling well prior to Trikafta.

Being on Trikafta now, I've had changes to some of my treatments since my health is so much better. This helped give me extra time back in my day.



*My first 5k at Stoneyfield in 2012 with my husband Eric*



*Post Boston Marathon 2021 with my husband*



# Lightning Round

## Favorite book:

The Harry Potter series

## Two songs on repeat at your house or during exercise:

I listen to podcasts a lot during exercise—especially Ally on the Run. I try to listen to music but then I want to sing which I can't do trying to run & breathe

## Love most about your dog:

I love their companionship and the funny things they do—zoomies, playing with toys, etc.

## Instrument played in concert band:

Clarinet

## First movie you ever saw:

Ooo, I can't remember the first one but I always loved *The Little Mermaid* and *Aladdin*.

## College degree:

Bachelors in Law and Government

## Favorite figure skating move:

I liked doing toe loops.

## Top three locations to which you have traveled:

Alaska; Lubec, Maine; Lake Placid, NY

## Favorite post run meal or snack:

Usually yogurt but a cheese burger and fries after a long run or race

## How do you prepare for your races?

I try to run about four to five times a week and make sure that I am fueling properly which is so important with CF. I also do a couple of stretching or yoga sessions during the week to help keep myself from getting an injury.

If we are doing a half marathon or marathon, I usually follow a training plan so that I'm ready to complete the distance.

## How has running changed you?

I feel like running and also living with CF have made me more resilient. Running for me is a challenge, but it also helps relieve stress. I did have a period of health decline a few years ago but still tried to walk as much as I could even though I didn't feel well.

I think the years of running helped keep my lungs strong enough until Trikafta became available. After Trikafta, I was able to get back to running and am feeling my best at 40 years of age.

## What advice would you offer someone who may want to take on a sport or other physical challenge, but doesn't know where to start?

When I was younger I would have never imagined that I would be a runner or physically active. There are even times now that I don't want to exercise but I try to tell myself that all I have to do is 15-20 mins and it usually helps me get going.

Try committing to 15 mins of activity and then try to build on that when you are ready. If you also have a friend or family member who is willing to join you it helps give you a support system and another reason to commit to making time for exercise.

*My first Trikafta dose with Dana Dorman*



# Wellness Tips from a CF Mom: Jennifer Stover

I started using daily intentions as a way to keep my own life on track with living well. My intentions are always changing but all work toward the same goal of living a balanced life. This schedule offers a variety of ideas to get you started.

**Motivational Mondays:** This is a great time to start an exercise program, start eating healthy, or work on a task you've been putting off. If you're finding it hard to get started, try breaking things down into small steps.

**Transformation Tuesday:** Personally, I use this day to reflect on the hard work my daughter has put in, to become this strong, healthy teenager. She has made quite a transformation in the last few years. I also think about how my life as a parent has transformed from the time she was born until now. So many ups and downs, struggles and celebrations!

**Wellness Wednesday:** Focus hard on making healthy choices today. Staying hydrated, getting 7–8 hours of sleep, eating healthy fruits and vegetables, taking a walk on your lunch break, and trying to have a positive attitude.

**Thankful Thursday:** It has been proven that gratitude helps people feel more positive emotions and improve their health. Being a CF parent has made me focus more on the important aspects of life. I have countless things to be thankful for and really do find joy in acknowledging them.

**Feel-good Friday:** Outside is my happy place, but that's not for everyone. On this day do what makes you smile. Whether it's playing your favorite music, calling your best friend, hanging with your family ... You get the idea.

**Social Saturday:** I am a people person. I love hosting parties and being around others. Unfortunately with covid, these activities have been considerably altered. Like others, we've found ways to safely socialize by zooming, gathering outside and compliant mask wearing.

**Self-care Sunday:** In preparation for the week ahead, Sundays are perfect days for your self-care routines. I've recently taken a liking to yoga and am on day 5 of a 30 day challenge. I also like to have some quiet time for myself and read whatever is on my nightstand. Part of my self-care Sunday also includes using a technique called Tapping. This is a stress relieving technique my co-worker taught me a few years ago when my daughter was struggling with her health and me with my stress management. EFT tapping (Emotional Freedom Technique) is a great way to relieve stress and reset whatever negative emotions are disrupting your body. Emofree.com is a great website that illustrates this technique and offers a video tutorial to help you better understand the concept. I even got my reluctant daughter to work with me on this until she was able to master it on her own.



# Wellness Tips from your Care Team

“I try to get outside for some fresh air and enjoy the Upper Valley with my fur-babes.”  
*Dr. Sanville*

“Fit in small bits of being present throughout your day. Mindfulness doesn't need to take long! Sometimes, just reminding myself to take one deep breath through my nose or stepping outside for a quick breath of fresh air helps re-center myself when I feel overwhelmed.”  
*Torie Miele*

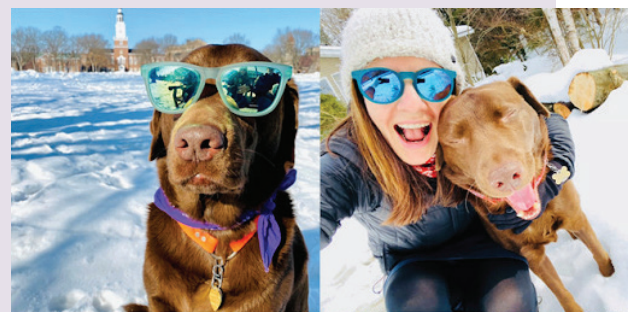
“To get outside every day for a walk/fresh air!”  
*Nicki Felicetti*

“Yoga and workout tapes six days a week”  
*Lynn Feenan*

“I routinely go to the gym, and practice yoga a few days a week at my home. I prioritize it in the morning, before anything else can get in the way because otherwise excuses or fatigue creep in. The gym is the one 'thing' I do and have come to as an acceptable 'risk' of me being in the community because it keeps me physically and mentally well. When all else fails—I go for a good run outdoors with my dog which also helps to keep me on track!” *Danielle Cantin*



Left to right: Jonas, Bernie



“Get vaccinated”  
*Kate Lamare*

# Dietary recommendations in the age of Modulators

By Paula Garvey and Emily S. Cooper

This is a hot topic issue and it appears that the research is still evolving. If you are taking Modulators, here are some questions you might ask your CF Care Team at your next appointment!

**Do I need to reduce calories?** It is probable that CFTR modulators will decrease caloric needs for many people with CF, and this should be discussed with your CF team.

**What type of fat do I need to take when taking my modulators?** You will need to eat a meal or snack containing fat when taking modulators. Use vegetable fat rather than animal fat when possible. Olive oil has additional health benefits for the heart and brain! Ask your team for suggestions for healthier meal/snack ideas.

**Do I need to reduce sodium?** This question is still being researched, so information may be evolving on this soon.

**Do I need to reduce the dose of my vitamin D supplements?** It is possible that you will more easily absorb vitamin D, so it is important to keep track of your vitamin D lab values, and discuss dosage with your team.

**Should I increase my physical activity?** The answer is likely yes! Most of America needs more physical activity. Whatever activity you choose to engage in should be enjoyable enough to encourage continued effort and participation. General recommendations for adults includes moderate to vigorous physical activity for 60 min 5 days per week. Be sure to always check with your doctor prior to starting a new physical activity routine.

Good nutrition is preventative medicine. Make good healthy choices when possible, and use healthy substitutions. Ask your team for ideas on healthy choices and check out recipes online!

Please always check with your team, and note that the CF Foundation has not yet updated its dietary recommendations when on modulators.

Recipes & Cooking Tips  
Everyday CF: [everyday-cf.com](http://everyday-cf.com)

[nurturlife.com/blog/healthy-alternatives-common-foods-better-diet/](http://nurturlife.com/blog/healthy-alternatives-common-foods-better-diet/)



# Roni's Corner

## Mindfulness & Self Care

Many people experience mood changes during the winter season. The grey weather, limited daylight hours, and chilly temperatures can impact our ability to feel joy. We've heard the term "self-care" a lot during this pandemic era, but what does it really mean? And how can we take care of ourselves at the same time that we have so much to accomplish every day?

Here is one idea: Author Meg Barker (2010) designates "kind" self-care from "reflective" self-care, writing, "Kind self-care practices are the kind of nurturing and self-soothing activities which build a sense of our being a person worth treating kindly ... Reflective self-care refers to the person taking time to focus on the way they are being and/or the conflict itself," (p. 14). Barker cites hot baths and small treats as two examples of kind self-care, and journaling and meditation as two examples of reflective self-care.

Most profoundly, Barker writes that balancing these two kinds of self-care allows one to establish compassion for themselves (through kind actions), while at the same time considering ethical responses to situations (through reflective actions). This framework may help individuals to feel both calm and more grounded in their identities. Consider developing a mixed self-care practice using the activities written below:

### Kind self-care ideas

1. Cook a nutritious meal from scratch.
2. Move your body joyfully
3. Watch a movie or TV show that you enjoy
4. Take a nap!



MJ 10 w/CF out for a cross country ski



RG 13 w/CF skiing with three and four legged friends

### Reflective self-care ideas

1. Meditate using an app on your phone or tablet. Many of these apps contain free content, with additional content available for a monthly subscription fee. Here are a few popular ones:
  - a. Headspace
  - b. Calm
  - c. MyLife Meditation
  - d. Smiling Mind
2. Call a close friend or family member to talk about your week.
3. Establish care with a therapist (call Roni or send a message on myDH for help!).
4. On the first day of every month, write down three things you are grateful for and three small things that you'd like to accomplish over the next month.

# The Rock CF Foundation

BREATHE DEEP. RUN HARD. ROCK CF.

Did you know that Rock CF will help you achieve your fitness goals by paying for entry fees for Races and Runs! AND you might be eligible for a FREE pair of cool sneakers too!

Rock CF is a community thousands strong changing the face of what living with Cystic Fibrosis looks like and giving those living with CF the tools to not only survive, but thrive.

Rock CF was started by Emily Schaller, an adult with cystic fibrosis. In 2004 Emily got the idea to bring awareness to Cystic Fibrosis by throwing a rock show for her friends, a few years later in 2007 Rock CF was born. What began as one woman on a mission to educate her peers through some banging drums and guitar licks has now, a decade later, evolved into a multi faceted organization inspiring people living with CF to lead more healthy lifestyles and bringing awareness about CF to the metro Detroit community at large. Rock CF is empowering individuals with CF to live healthy lifestyles, through their **Kicks Back Program**, race sponsorships, and nutrition coaching. Their annual **Half Marathon in Detroit**, and apparel line has helped to fund research through the **Cystic Fibrosis Foundation**.

Rock CF is heightening awareness and making sure that an illness that often goes unseen, doesn't get forgotten.



500+

PAIRS OF SHOES

DONATED ACROSS

46 STATES

Whether it's your first run to the corner or 10th marathon, we are **empowering** people to boost lung function through exercise. **OUTRUN CF.**

**KICKS BACK**

The infographic features a large pink '500+' with a teal and white sneaker illustration integrated into the zeros. Below this, the text 'PAIRS OF SHOES' is written in pink, followed by 'DONATED ACROSS' in white on a pink arrow pointing right, and '46 STATES' in pink. To the right, a paragraph of text explains the program's goal. At the bottom right, the 'KICKS BACK' logo is displayed in black with a lightning bolt graphic.

Check out the program

[letsrockcf.org/kicksback](https://letsrockcf.org/kicksback)

And apply for free sneakers

[form.jotform.us/71215400770142](https://form.jotform.us/71215400770142)

[letsrockcf.org](https://letsrockcf.org)



# Pulmonary Function Tests (PFTs)

Sarah Vooris and Katie LaMare

Pulmonary function tests (PFTs) give information about how well the lungs are working. Measurements of lung function from PFTs help the CF team make decisions on diagnosis and work with you to create treatment plans. They are one tool used to check on your lung health.

Children with CF typically begin to complete PFTs around the age of six. Whether you start performing PFTs at six or 36, these tests take practice. A member of the CF team will teach you. It takes time to learn and produce consistent, reliable measurements.

Normal measurements vary from person to person. Your test results are compared to the average for someone of the same age, height, sex, and race. A member of the CF team will explain your PFT results and answer any questions you may have.

For times when you may look over your results on your own and need a reminder on what the common measurements and their abbreviations mean, here's a quick list.

## Common measurements taken with PFT (pulmonary function test):

**Tidal volume (VT)** the amount of air inhaled or exhaled during normal breathing

**Vital capacity (VC)** the total amount of air that can be exhaled after inhaling as much as you're able

**Forced vital capacity (FVC)** the amount of air exhaled forcefully and quickly after breathing in as much as you can

**Forced expiratory volume (FEV1)** the volume of air exhaled during the first second of the forced vital capacity (FVC) test

**Forced expiratory flow (FEF)** the average rate of flow during the middle half of the forced vital capacity (FVC) test

**Peak expiratory flow rate (PEFR)** the fastest rate that you can force air out your lungs



*L completing PFTs as a child during a clinic visit*



*L 15 years later with her own daughter*

PFTs

# Why I Vaccinated My Child

by Dave Robinson

To answer that I think I first need to tell you a little about my family and my daughter. My daughter is 6 years old and was diagnosed with cystic fibrosis at birth. She is what I would call strong-willed. A trait that will do her well in life, especially when battling this disease. She gets that trait partially from her grandmother (Nana), my mom. I grew up in a household surrounded by healthcare and medicine. My younger brother was born very premature and with a lot health problems. My mother did her due diligence and advocated for my brother, never taking “no” for an answer. However, she also put a lot of trust and faith in the doctors, nurses and specialists who surrounded them and that paid off. Watching that firsthand has helped me do the same for my daughter. Since birth my daughter has spent over six weeks in the hospital and has had two major surgeries. Through that experience plus the day-to-day experience of communicating with her amazing care team, I have learned the ebb and flow of advocating but also working together and listening to those who have spent their entire professional lives caring for those like my daughter.

When the Covid-19 vaccine was going through the initial authorization for adults, my wife and I talked in depth with our daughter’s care team about it getting it for ourselves as caregivers but also having our daughter get it once she became eligible. We asked many questions as we always do with every healthcare decision. We talked at length about the mRNA technology in the Covid vaccine and how that same technology has been used in the CF modulators that we are so lucky to have at our fingertips. If we didn’t have this science, we would not have the hope we have today for our daughter’s future. We did our due diligence and at the recommendation of the CF care team, we easily made the choice to get ourselves and our daughter vaccinated. We have trusted these healthcare professionals for years and taken their advice time-after-time only to see success within our daughter’s health. If we have trusted their professional opinions throughout other incredibly important healthcare decisions, why would this be different?

Ahead of our daughter getting the vaccine, my wife and I talked to her a lot about getting it and how important it was to her health and the health of other vulnerable people around her, like her uncle for example. We explained how it doesn’t just protect us but it helps those on the front lines who are fighting this pandemic. And when the day came for her to get her vaccine, she was proud to say she got it. She couldn’t wait to tell her friends and it’s what she shared in show-and-tell the very next day.

While the world we are living in right now isn’t easy, one thing our family can count on is our daughter’s incredible care team and the science we have trusted for the last six years, which has kept our daughter healthy.





# Recipes

## Mediterranean Style Turkey Burger

These low fat Turkey burgers are a family favorite. Turkey is a great low-fat source of protein. If following a gluten free diet, use gf breadcrumbs and gf burger buns

### Ingredients

1-lb ground turkey meat

1 egg

1 small onion (chopped)

1 clove garlic (crushed)

½ cup breadcrumbs

1 tbsp tomato puree or ketchup

1 tbsp chopped fresh herbs or 1 teasp mixed dried herbs

½ cup feta cheese

1 cup shredded spinach

¼ cup chopped black olives (optional)

¼ cup chopped sundried tomatoes (optional)

Pepper to taste!

2 tbsp oil (for cooking!)

To serve: 4 whole wheat buns, lettuce, tomato and onion for serving and topped with tzatziki!

### Directions

1. Place all burger ingredients in a bowl
2. Using your CLEAN hands, mix all the ingredients together
3. Divide the mixture into 4 equal pieces.
4. Shape into patty approx. ½ inch thick.
5. Heat oil on pan. Carefully place patties on hot pan. Turn down heat to medium, cook for 4 minutes. Carefully turn and cook on other side until temp reaches 165°f

These burgers are great on the grill too!



## Vegan Superbowl Recipe Buffalo Cauliflower Wings

Prep Time: 5 mins | Cook Time: 25 mins | Servings: 3 servings

### Ingredients

1 cauliflower chopped into big florets

cooking spray

½ cup flour of your choice, I used whole wheat

½ cup milk of your choice

3 tsp onion powder

2 tsp chipotle powder

salt and pepper to taste

½ cup bread crumbs of your choice

¾ cup hot sauce of your choice

½ cup agave, maple syrup or honey (you may want to add more depending on your spice tolerance)

1 TBSP coconut oil or vegan butter, melted

2 tsp onion powder

sriracha to taste, (optional)



### Directions

1. Preheat your oven to 450 F. Prepare a baking sheet with foil and cooking spray, set aside.
2. Prepare the batter by mixing the flour, almond milk, onion powder, chipotle powder, salt and pepper. If the mixture is too thick, add more almond milk. If it's too thin, add more flour.
3. Pour the breadcrumbs in a separate bowl. Dip the cauliflower in the batter and use your fork to scrape off any excess. Then coat the cauliflower in the breadcrumbs, shake off excess crumbs and place on the baking sheet. Repeat until you've done this with all of the cauliflower florets.
4. Bake for 20 minutes at 450 F.
5. While the cauliflower bakes, prepare the hot sauce mixture. Combine the hot sauce, sweetener, butter/oil, onion powder and sriracha if using in a bowl. Stir well and taste – then adjust flavors as necessary.
6. Pour the hot sauce mixture in a small saucepan and cook it on medium heat for about 5 minutes. This helps bring out the flavors.
7. When the cauliflower is done baking, toss it in the hot sauce mixture, coat it as well as you can, and return it to the baking sheet. Bake for another 5 minutes.

From: Work Week Lunch, <http://workweeklunch.com>

## Cystic Fibrosis Foundation – Northern New England Chapter

# 2022 SPECIAL EVENTS

Northern New England Chapter Office: 20 Trafalgar Square, Suite 447, Nashua, NH, 03063  
603.598.8191 or 800.757.0203 | [northern-newengland@cff.org](mailto:northern-newengland@cff.org) | [www.cff.org/newengland](http://www.cff.org/newengland)

Executive Director: Lisa O'Connor

Stay connected! Follow us on:

Facebook: [facebook.com/CFNNE](https://facebook.com/CFNNE) Twitter: [twitter.com/CFNNE](https://twitter.com/CFNNE) Instagram: [Instagram.com/CFNNE](https://Instagram.com/CFNNE)

## Special Events



**Ski for the Cure**  
**Virtual Program: March 10, 2022**  
The CF Foundation's Northern New England Chapter has decided to make our 2022 event virtual once again this year as nothing is more important than the health and well-being of the CF community. We hope you will continue to advance our mission to cure cystic fibrosis by supporting this incredible event! Please join us virtually on March 10, 2022 at 7pm as we celebrate together – it will be a moment you won't want to miss!  
<http://fightcf.cff.org/skifortheCure2022>



**Great Strides Walks**  
**Save The Date ~ May 14 & 15, 2022**

Great Strides is the CF Foundation's largest fundraising event. It provides opportunities for all people within a local community to get involved forming teams with friends, family and colleagues. **For more information:** [visit greatstrides.cff.org](http://visitgreatstrides.cff.org)

**Augusta**  
**Lancaster**  
**Rutland**

**Bangor**  
**Nashua**  
**Seabrook**  
**York**

**Hanover**  
**Portland**  
**Wolfeboro**



**New England Classic Charity Trail Ride**  
**June 10-12, 2022**

Riders from all over the U.S. and Canada descend upon NH for a weekend to remember! Riders enjoy hundreds of miles of trails, lunch both Saturday and Sunday and much more!

<http://fightcf.cff.org/nhcharityride>



**Cycle for Life**  
**July 2022**

Join us as we ride through some of the most picturesque and scenic terrain along the coasts of Maine and New Hampshire. CF Cycle for Life is a fully-supported ride with route options of 30 miles, 65 miles or a Century. From breakfast to our post cycle lunch party, you can enjoy fully stocked rest stops, bike mechanics for bicycle maintenance and repair and plenty of support vehicles to help you complete the ride. This unique event empowers participants to take action and demonstrate their fight in finding a cure for cystic fibrosis in a tangible, emotional and powerful way.



<http://fightcf.cff.org/seacoastsafari>



# Special Events

## GREAT STRIDES

CYSTIC FIBROSIS FOUNDATION



### Great Strides Fall Walks

Bar Harbor, Maine– September 17, 2022  
Burlington, Vermont– September 18, 2022  
Belfast, Maine– September 17, 2022

### Swing for CF Charity Golf Classic

TBD

Breakfast Hill Golf Club  
Greenland, NH



Save the date! Golf at one of New England's premiere golf clubs, all for a fantastic cause! All playing spots include green fees, cart, tee gift and meals. Spots will be limited for the 2022 year so make sure to register early.



### Taste for a Cure

November 3, 2022

Join us for the 15th anniversary of Taste for a Cure, and explore the fabulous auction just in time for winter holiday gift giving!



### Three-Day Stampede

TBD



### Barrett's Halloween Benefit

TBD



## CF Foundation Programs

### GRAMPIONS

CYSTIC FIBROSIS FOUNDATION

A CF Foundation Grampion is a grandperson who is passionate about helping those with cystic fibrosis (CF) live their best life. They are the ultimate champions for not only their grandchild but others' grandchildren.

Grampions **CORE**:

What are the key components of the Grampions experience? *Community, Outreach, Relationships and Education.*

**Community** - Grampions support each other in their "CF Journeys" and in their Efforts to support the mission of the Cystic Fibrosis Foundation.

**Outreach** - Grampions work together to increase awareness of cystic fibrosis and the CF Foundation's mission in their communities, including policy-makers.

**Relationships** - Grampions foster relationships among their group, their local CF Foundation Chapter

**Education** - Grampions have access to learning opportunities about CF and related issues as well as resources that may benefit their loved ones and other information on a wide range of topics.

The Northern New England chapter will be holding a Virtual Grampions event on Monday September 28th. To register for the event please email [northern-newengland@cff.org](mailto:northern-newengland@cff.org)

# CF Foundation Compass



Contact CF Foundation Compass today  
Tell them your issue  
**They will help you find a solution.**

844-COMPASS (844.266.7277)  
[Compass@cff.org](mailto:Compass@cff.org) [CFF.org/compass](http://CFF.org/compass)



CF FOUNDATION COMPASS CAN HELP WITH THAT.

## 2022 Virtual Events

### CF MiniCon: Transplant– TBD

A free online event that will provide a space online for adults with cystic fibrosis, their families, and caregivers to explore all stages of the transplant process, including considering a transplant, preparing for transplant, or post-transplant.

### ResearchCon: TBD

ResearchCon is a free online event co-led by clinicians, researchers, and community members to share the latest around CF science and research for anyone with a personal or professional connection to CF. [Sign up](#) to receive email updates on virtual events and be notified when registration opens and agendas are posted.

## Become a Tomorrow's Leader



CYSTIC FIBROSIS FOUNDATION

*Be an Advocate*

*Be a Volunteer*

*Be a Supporter*

**Who we are:** Our Tomorrow's Leaders Council (TLC)

Consists of dedicated and energetic young professionals who are committed to Supporting the Mission of the Cystic Fibrosis Foundation.

For further information, contact the Northern New England Chapter at: [northern-newengland@cff.org](mailto:northern-newengland@cff.org)

**What we do:** Throughout the year, the TLC will host events and other engagement and networking opportunities to help support the mission of the CFF. The extent of your involvement is up to you. TLC members can attend all or some of the events or programs. Members can also take a leadership role within the group, helping to plan and coordinate events and networking opportunities.

### **Upcoming Virtual Events:**

TBD

## The Importance of CF Advocacy

Federal and state governments play a vital role in CF research, drug development, and the ability of people with CF to access the care and therapies they need. You have the power to inspire action and help shape public policy. Learn how you can help make a difference. By texting **FIGHTCF** to **52886**, you can stay in the loop with the Foundation and how we're fighting for people with CF. You'll receive periodic communication about upcoming legislation, how to contact Congress, and how you can get involved.

## Individual Giving

### Annual Fund

Your gift of support to the Annual Fund provides important, unrestricted resources that help us accelerate our efforts to pursue a cure for cystic fibrosis, fund development of new therapies, and help all people with cystic fibrosis live longer, healthier lives.

<http://www.cff.org/annualfund>

**65 ROSES CLUB**  
CYSTIC FIBROSIS FOUNDATION

**Join the Club.**  
**Help make CF stand for Cure Found.**

There is an easy way for you to show your commitment to advancing the mission of the Cystic Fibrosis Foundation. The [65 Roses@ Club](#) is a group of CF Foundation donors who provide consistent support each and every month. These monthly donors are united by their commitment to a common mission: helping to make CF stand for Cure Found. Their steadfast support provides a steady, reliable stream of revenue that enables the Foundation to accelerate innovative research and advance care and advocacy for all those living with CF. [www.cff.org/Give-Monthly](http://www.cff.org/Give-Monthly)