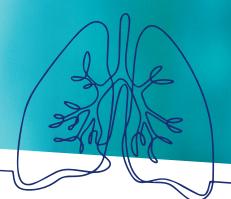
# CYSTIC FIBROSIS Patient Family Advisory Council



#### Fall Issue 2023

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 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?

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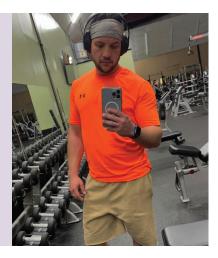
and much more



### **CF Community News**

#### Drew at the Gym

"The Gym saved my life! Some days I don't want to do the work. Some days I'm exhausted. Some days I'm running on empty. The gym is my unlimited iced coffee. The gym is my gas station. A brutally honest friend that always has your back. The gym is the fuel that feeds my soul. Hard work is my path to happiness."





#### **Berlin Marathon**

Congrats to our PFAC
Board Member, Kerri,
on completing the Berlin
Marathon! Kerri has
completed the Boston
Marathon 3 times!!!

Well done Kerri!



#### Wild Flower Festival

Congrats to Griff for organizing an amazing event in Milford. Local musicians and crafters gathered to raise awareness of the importance of bees in our world. The money raised at the festival will help establish pollinator gardens for bees.

#### **CFF Cycle For Life**

The CF Foundation Cycle for Life (Seacoast Safari!) was held on July 15. One hundred cyclists rode new routes of 100 miles, 65 miles or 30 miles to raise awareness and funds for the CF Foundation. Mother Nature cooperated and it was a perfect day to enjoy the fabulous New England coastline. Thanks so much to all who participated and volunteered to make this event so great—\$140,000 was raised to benefit the CF Foundation. It was great to see so many familiar faces there participating and volunteering. A huge Congrats to Dana Dorman who was presented with The Commitment To Excellence award—thank you Dana for all the work you do for this event. Looking forward to Cycle For Life 2024 on July 13, 2024.





## Congrats to Mallory

Mallory recently obtained her CPMA and is now officially a Certified Professional Medical Auditor. "It took me years of hard work and studying. I'm super proud of myself"

# **Back to School**



Aubree is excited to start 3rd grade



Colbee's first day of kindergarten!



Cadie is ready for an amazing school year



Hailey started Senior Year! Cheers to the class of 2024!



Monica aka Mosey started 5th grade!!!!



Lucas's first day of Freshman Year!!



Hannah starts Senior Year



Regan started High School

Have a great school year everyone!

## Annual Retreat

#### Report from CF Retreat, Sunapee, Sep 23

By Paula Garvey

Life is busy so every Fall our CF Team puts aside time to meet and to discuss relevant topics in person. It is a unique opportunity to discuss the past year, how we did, and how we can improve in the future. Here is a brief overview of the discussions.

We have over 200 CF patients at Dartmouth Health and CHaD CF care Center. Dr. O'Sullivan and Dr. West shared information from the CF Registary—this information is gathered so we can learn from it and it helps improve care delivered to our patients and families. The information will be presented at Patient and Family Education Night on November 15.

The team is very grateful to all patients who participate in trials. Dr. Sanville shared information on exciting trials that are happening at our center, please ask the team for details if interested in participating.

There is a focus group working on making transition from pediatric to adult care more streamlined. If you would like to be part of the PFAC Transition project please email us or let a member of your team know.

It was noted with modulators that patients are feeling well and are less inclined to come to clinic, this creates a challenge for the team as it is more difficult to get to know the patients and their needs. So, PLEASE come to clinic!

We got a report on diabetes screening and also an update on Dietary guidelines. More guidance is needed, especially with regard to salt intake. Overall an individualized approach on diet works best.

Dr. Martha Graber presented very interesting information about the incidence of kidney disease in the CF population.

MOVE with Roni kept us active between presentations and we appreciated the reminders to stretch and breathe! She also reassured us that Molly and her are very much in tune with the needs of our patients and families. She worked with the team to encourage collaboration with care management

Childlife gave us an update on Mindblown Kits—please check in with them for more information on these amazing educational resources developed by one of our own PFAC members.

In a complicated world of insurance and co-pays, we are very fortunate to have a pharmacist on our team to help patients and families navigate the system. Please connect with Emily and Roni if you have questions or concerns. CFF Compass is also a great resource.

Parents Kristin and Brian McCarthy attended and had this to share: "We were thrilled to attend the retreat as parents. It was so inspiring and reassuring to see how dedicated the team is to studying and improving each metric measured by the foundation. We were grateful that our input and comments were heard and taken seriously, and that the presenters/attendees explained topics in fairly plain language. Their passion and vested interest in improving the lives of the CF community was quite heartwarming."













If you have any questions on the topics discussed, please contact any Team member. A HUGE thank you to Emily and Nicole for organizing this retreat. And lastly, don't forget to wear a mask when in the hospital!

#### A message from

# Nicole Czyzycki, Pediatric Cystic Fibrosis Center Coordinator

Hi Everyone,

I hope you've had a good start to the fall. Cold and flu season are coming up on us quickly. I've already had the first cold of the season pass through my house! Flu vaccines are available in clinic. If you get them with your primary care doctor or at a pharmacy please let us know so we can record it in your child's record.

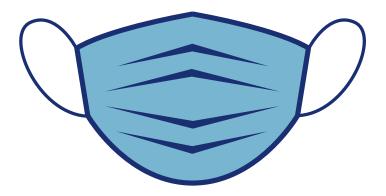
There is a new COVID booster available and recommended for everyone 6 months and older. Vaccination is important to help reduce your risk of contracting COVID and helps minimize the effects of the illness if you do contract it.

Masks are recommended by the CF Foundation whenever entering a medical facility regardless of the time of year or viral spikes. Masks are available when you enter the building, at registration, and can be requested when you enter the department.

As always good handwashing, covering your cough, and taking care of yourself (sleep, nutrition, etc.) are the best defenses against serious illness.

Hope everyone has a very healthy fall and winter!

Nicole



# Spotlight on Nicholas Kelly

Our upcoming speaker for Family Night, Nick Kelly, is an adult with CF. Nick has extensive connections with the CF community—from CF ambassador and advocate to Great Strides DJ, chapter board member, Rose Up committee member, and more. A son, friend, sibling, dietitian, author, and artist, Nick's life is shaped by CF, but the disease does not define him. Read our recent interview to understand more about what drives Nick to continue engaging with the CF community to promote positive change. This interview has been edited for length and clarity.



Tell us about your diagnosis with cystic fibrosis. How did that come about? As a child, I was really sick and went through a stretch where "no one" could figure out what was wrong with me. It was my mother who diagnosed me because 36 years ago now, they didn't believe African Americans could have the disease. And so because they didn't believe they could have the disease, no one would test for it. As I continued to get sicker, it was my mom who learned the symptoms and she did the research. She went to the hospital administration and said if you don't test my child, I will go to every news outlet and let them know your prejudice killed my son.

It's a common misconception that CF is only a caucasian disease and your mom really advocated and fought hard for you. Yes, and sadly, a lot of that rhetoric still exists today.

**Are you eligible for modulators?** No. I have a super rare mutation—two nonsense, super rare mutations. I'm not modulator eligible.

We all need to keep up the urgency to find more treatments and a cure, we're not done yet and need to keep advocating and doing what we can to create options for everyone. How do your parents continue to encourage you to keep learning and advocating in your life? My mom is a super smart firecracker of a woman. She and my father instilled in my siblings and I a drive for learning and a drive for education. Every day growing up my dad would say, "when it comes to school, I don't play." That was a mantra in our house. You look at my mom's continuous quest for knowledge and it translates into me and my siblings. We all have multiple degrees as the value of education and the learning process was kind of our fabric. I've done a lot of self-learning. We pursue our interests and get information.

Besides with your educational standpoint, how did that mentality of being curious and always learning play into other parts of your life growing up? Like understanding CF and your independence? One of the big things that happened throughout my childhood was being told to be independent with my disease. So growing up I was very independent. I was treated normally and that was a

huge thing. That's one of the huge things I would stress to any parent—let your kids be kids, you know? That's what my parents allowed. They carried a lot of the burden, the weight on their shoulders, so I didn't have to, but I was able to incorporate things into the daily routine. We would play games with taking my enzymes—how sly could I take them without people noticing? All CF care was incorporated into the daily routine and it didn't feel "off." It was just something I did. My parents instilled in me that having this disease doesn't give you an out, you have to be held to the same standards. I traveled, did all the things they did, and adjusted accordingly. Like on a hike, I could stop and rest, but I still got to go on the hike.

I always say CF does not define me, but it has shaped who I am. And that was always (and still is) a really big thing for me. Each segment of my life has kind of been different points of information, advocacy, and action. I have this information and now I put it into action and much later in the future it becomes advocacy. When I was younger, I learned how to advocate for myself. People love you. People can help you. But, at the end of the day, it's your health and thus it's your responsibility.



Getting to know you through your online presence, I was struck by your reference to gratitude and finding gratitude in the expected and the unexpected. Describe how you came to your current perspective on gratitude. Many things have happened in my life that I've had to take perspective on it (gratitude) basically. I navigate situations and go through it because that is the way I had to come out on the other side. Learning that if I can appreciate the suck, if you will, it will allow me to navigate the hard times better. I'm a public speaker now. But, public speaking actually came from the worst thing that ever happened. It was when my cyster passed. She would always tell me as we were growing up, she'd be like, "Nick. Tell your story. You could help someone, Nick. Tell your story." When she passed, I was broken. The only way for me to heal was to start telling our story. And she would always say I could really help someone by telling my story. I never knew I'd be the one it was helping. Losing her is a prime example of suck becoming gratitude because it led me to a passion I didn't know I had.

Those really horrible things, and they all don't have to be extreme, they can be life lessons. Some of these things make us stumble, fall, get back up, and teach us to appreciate the stumble. You have to be appreciative of the fall, because that fall can very well teach you the lesson that you now know moving forward.

Besides a public speaker, you are also an author. How did you become an author? Growing up, it was basically the three musketeers—Nick, Shell, and me. Nick and Shell always talked about wanting to write a children's book. Nick passed when I was 17 and Shell passed when I was 25. I mentioned how broken I was over both of them. And so fast forward, I was in the hospital one day and one of my nurses, Maria (who's also a good friend of mine), were talking. We were discussing how CF has this fear around it. For younger kids and kids growing up because of how people discuss it. We wanted to make it fun and make the learning of CF less fear related—to make it kind of enjoyable and more imaginative. Maria and I talked about it and decided to create a book. It was a situation where I felt like writing the book was a promise kept. We co-authored the book and I'm the co-illustrator. I'm in the midst of editing book three of the children's book series on CF.

What other mediums of art do you find fulfilling? Why do you think creativity and expression in the arts is important for you and others? The arts is one of my biggest passions. Passion is the single greatest thing a person can have. When you have passion, it leads to purpose. Purpose leads to productivity. And for me, those passions are things that are extremely important. Poetry is my first love. It was the first thing I started doing, the thing that changed me. My second art passion is dance. I was a professional dancer for 12 years. After dance came photography. I'm a professional photographer. I've done most things in the art world.

The reason I think the arts are important is because of passion. When a person has passion, it allows them to find purpose - purpose inside of passion. It allows them to heal, allows them to navigate, gives them strength, allows them to engage. One of the examples I always give is with treatments. You have all these CF treatments to take and you never want to get to the point where you're taking a treatment just to take another treatment. Like with a car, you never want to have a car, to just merely drive from one gas station to the next gas station. You want to go to the gas station so you can then do all the things you want to do, like go to the mall, the movies, etc. After all of that you need to go to the next gas station. Passion is going to that movie or other thing between having to fuel up. The purpose now of the treatments is to get from passion to passion.

Why did you "write" the poem Rise Up for a Dream and what do you want people to understand about you from it? Random fact, I actually did not write anything down, 100% of that poem is freestyle. It was the truest manifestation of passion in the moment. The poem was for this major Breathe Life Gala. But the idea is that I'm just one voice in a sea of many. However, I have a platform. I am a platform to express. Express different feelings, express advocacy, express many of the challenges most of us are going through. It is a skill I have to be able to project that and advocate for that in different ways. I'm not just talking for myself. It's not just about Nick Kelly. It's about all of my sisters and brothers with CF. Having the ability to be able to speak is the legacy I'm building. That legacy is going to be built, I believe, on the people I can affect and the people I can impact.

When things are hard, how do you get back to a firmer place of your "why"—why you take your meds, do your vest, etc? I have multiple passions I can navigate. I think finding things you are passionate about and using extensions, like a touch point to grab and hold onto, or a place from which to start looking for something that can cultivate you in a different way, helps.

Thus, when I'm not feeling passionate, I make a switch. I lean into a different passion or start finding things that cultivate new passions.

How does your career as a registered dietitian fit into all of this? Becoming a dietitian is actually a funny story. I originally went to school for computer technology. I wanted to build the biometric scanners the FBI uses. When I got to school, they had rolled the computer tech and computer science programs together. I've coded in five different languages and I hated all of them. I started looking around at other options for school. In the meantime, my twin sister went to the same school for biology and later nursing. She was taking a nutrition 101 class and did not want to take it alone. We struck a deal that was fantastic for me. The next day in class, the way the professor (Dr.Joe) talked about nutrition made it like the greatest puzzle I'd ever heard. I was so blown away. I called my mom and asked her,



"How do you feel if I was a dietitian?" I changed my major that day. I'm currently in the process of publishing a high calorie cookbook: "No Need for Seconds."

What are some things that may be next for you? What are you curious about? I'm currently looking for my next project. I'm in the process of looking because I feel like I've done a lot, but I always feel like I haven't done enough. And so there's more to be done. I'm leaning into my current passions more because I feel like if you get engulfed in passion, it helps you gravitate towards new passions. Passion begets passion.

Given the changing nature of life with CF (emergence of modulators, new treatments, genetic therapy trials, etc), what do you think are some of the challenges facing the CF community today? One challenge is the lack of diversity. They're trying to make efforts to make it better, but the lack of diversity, equity, and inclusion really needs to be worked on.

Another challenge is helping people understand what is meant by the concept of a "pipeline." It seems to be a vague term and there is a lack of fundamental understanding about the disease and the things that are

happening and coming up as possibilities to improve lives. There's a knowledge and information gap about the pipeline.

Any last comments you want to share? The thing that defines Nick Kelly more than anything is what his legacy is and how that looks, what he does to shape that legacy and the impact I have on others. The difference I can make. The growth I can have in myself is what defines me and what shapes what I want to do with my life.

#### Links to Nick's Books:

- The Adventures of Miss Messy Suzie McGoo and The Cuff Cough Crew
- The Adventures of Miss Messy Suzie McGoo and Her Respiratory Zoo

Links to the poem Rise Up for a Dream

#### **Lightning Round**

Bagpipes or piccolo? Bagpipes

Dogs or cats? Cats. Easy.

Sweet or salty? Sweet

Haiku or sonnet? Sonnet

Oils or watercolors? Watercolors

Chocolate or gummy bears? Gummy bears

Harry Potter, Lord of the Rings, or neither? Neither

Tea or coffee? Tea

Night person or morning person? Night

Jazz or opera? Jazz

If you could travel anywhere in the world, where would you go? I want to see four of the seven Wonders of the World, the Northern Lights, and the Great Barrier Reef.

Movies or TV? TV

Mountains or ocean? Ocean





New Hampshire CF Patient and Family Education night

GRAPPONE-MARRIOTT CENTER, CONCORD,
NEW HAMPSHIRE
5.00-9.00PM WEDNESDAY NOV 15TH 2023

#### <u>Agenda</u>

5pm: Time with vendors and CF Foundation
5:45pm: Introduction and Welcome with Paula Garvey and Nicole Czyzycki
6:00pm: Dinner served

6:00pm: Updates from NACFC from Paula Garvey and Sarah Vooris

6:15pm: Research updates with Dr. Aridgides and Dr. Sanville

6:25pm: NH CF Center Updates with Dr. West

6:35pm: CF Foundation Registry review with Dr. O'Sullivan

6:45pm: Break, time with vendors

7:15pm: PFAC updates with Paula Garvey and Sarah Vooris

7:25pm: CF Foundation: Northern New England with Lisa O'Connor

7:30pm: Keynote Speaker: Nicholas Kelly

8:30-9:00pm: Time with vendors

LIVE STREAM WILL BE AVAILABLE, Zoom link will be shared BEFORE the event.

WE WILL FOLLOW THE CYSTIC FIBROSIS FOUNDATION'S ATTENDANCE POLICY FOR INDOOR EVENTS,

ONLY ONE PERSON WITH CF WILL ATTEND

Please email nhcfpatientfam@gmail.com for details

Please RSVP here by Oct 15th



# Advocacy Update

Fall 2023

Advocacy for the passage of the PASTEUR and HELP Copays Acts continues as we work to get members of congress to cosponsor the bills. The PASTEUR Act addresses antimicrobial resistance and the urgent need for antibiotics and other novel medicines to treat difficult infections (like those caused by MRSA and pseudomonas). HELP Copays focuses on access and affordability of the highly specialized care needed to stay as healthy as possible with cystic fibrosis.

With more congressional cosponsors, PASTEUR and HELP Copays have a greater chance of becoming law. Currently, Congresswoman Annie Kuster of New Hampshire cosponsors both bills. Congressman Chris Pappas (NH) cosponsors the HELP Copays Act. We need more members of congress to support the bills in order for them to become law.

#### As members of the CF community, you can help.

To advocate directly text "FIGHTCF" to 96387 or check out\_act.cff.org/tYteTfQ. You will receive advocacy alerts and information from the CF Foundation, including resources to directly communicate with your Senators and the House Representative in your district.



# Where to Next Travel adventures with CF

by Mickey Noyers

Some of my earliest memories are of family camping trips in the White Mountains and down on Cape Cod. For many years, when my kids were tweens and teens, my family went on a cruise every couple of years. I also have very fond memories of the 10 days I spent driving cross country from Yellowstone National Park to NH. I have always loved to travel and that love has only gotten stronger the older I get. The difficulty of making it happen, however, has also increased the older I get.



I am a 50-something year old woman with CF and as such my treatment regimen looks a lot different now than it did when I was younger. Traveling

for me these days takes a good deal of preplanning. I now do 9 nebulizer treatments a day and use supplemental oxygen, but still, when someone mentions going on a road trip, my only question is, "When is the car leaving?" (so I can make sure I'm in it!). Through trial and error, I have come up with some tricks that make traveling easier for me.

The first thing I think about is making sure I have power to run my nebulizer if I'm going on a camping or road trip that doesn't involve hotels. For an extra fee you can sometimes get car adaptors that will plug into the receptacle on your dashboard and power the different devices when the car is running. For me, this meant not only spending a bunch of extra money to buy the necessary adapter cords for each device, but also having to constantly sort through the pile of cords to find the right one when I wanted to use it. It was a happy day when I found a "Car Plug Adaptor Outlet Converter." This allows me to plug the converter into my car plug and then plug any electrical device into the standard outlet on the adaptor. I use this for my nebulizers and also to recharge the batteries in my portable oxygen concentrator. Quick and easy! I got mine years ago at Walmart, but they are also available at Amazon and BestBuy.

The other part of this nebulizer thing I found super annoying was the way I was packing my medications. Those that didn't need refrigeration I put together in one bag which meant I was having to repeatedly fish through to find the ones I needed. To help with this problem, I now use a small, desk-top size, plastic 3-drawer unit. I put all my medications, insulin pen needles, and glucose testing supplies in this unit. Everything is visible, all in one place, and easily accessible. It takes up slightly more space than my previous shove-it-all-in-a-bag method, but this is well worth it for the time and frustration it saves me!

I thought my travel days were pretty much over when my doctor told me I needed to start using supplemental oxygen. In addition to all the nebulizer stuff, how could I possibly lug around all the oxygen supplies? Would there

still be room in the car for my family? Luckily for me (and for them!) I've figured out a couple things that make this work. First, I get my oxygen tanks from a company that has offices nationwide. On the Yellowstone road trip, for example, I brought along a few tanks and planned our route so we passed one of the company's offices every few days so I could swap out my empty tanks for full ones and pick up any other supplies I might need at the time. When we were going on a cruise, the company's office closest to our departure point was able to drop the tanks I needed right at whichever hotel we stayed in the night before we boarded the ship. When the trip was over, I returned the empty bottles back to the same hotel and the oxygen company picked them back up. This works well as long as I make all the arrangements with the company at least 3 weeks in advance of the trip.

My children, just this Spring, have all graduated and are off on their own adventures. I am currently in the process of turning the back of my pick-up truck into a camping setup so, along with my yellow lab Quincy, I can take some road trips to see parts of the country I haven't seen before. It is a custom build with the typical space for sleeping, cooking, and a sitting area for reading or working on my computer. It also has dedicated space for a small, solar powered generator which will run my nebulizers and oxygen concentrator, a highly insulated cooler to keep medicines cold for several days, and a rack for storing a few oxygen tanks.

# The only question that remains is, "Where to next?"





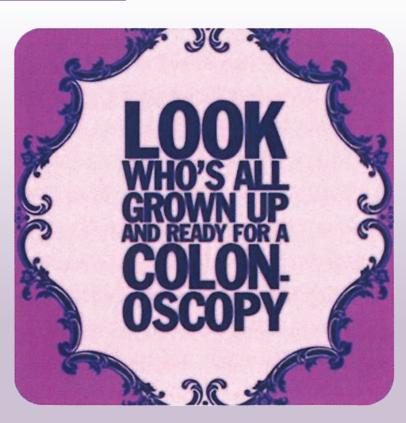
# Colon Cancer

Improved therapies have substantially increased survival of persons with cystic fibrosis. But the risk of colorectal cancer in adults with CF is 5-10 times greater compared to the general population, and even greater after an organ transplant.

To address this risk, the CF Foundation has guidelines for colorectal screening in adults with CF. The guidelines recommend colorectal screening by colonoscopy starting at age 40, with rescreening every 5 years. Screening colonoscopy is the best method to resect pre-cancerous colon polyps and prevent the development of colorectal cancer. This procedure can either be scheduled locally by your primary care physician or your CF Team will gladly assist you in scheduling a colonoscopy.

Check out this video from CFF

Learn more by checking out this info from the CFF



# Roni's Corner

Every year I hear a common theme from patients when the temperatures start to drop: winter anxiety. Folks worry about the cost of heating fuels, the emotional impact of short days, and the need to stay inside due to cold weather. Winters in New England can feel long and hard. Let's talk about how to get through them.

#### For Fuel Assistance:

- Both New Hampshire and Vermont both have fuel assistance programs for families who qualify. There are also several tax incentives and rebates for homeowners who seek to make their homes more energy efficient (and therefore cheaper to heat!).
- New Hampshire: go to <u>energy.nh.gov/consumers/help-energy-and-utility-bills/fuel-assistanceprogram</u> to learn more.
- Vermont: go to dcf.vermont.gov/benefits/fuel to learn more

#### For the emotional impact of short days:

- Light therapy: This Harvard article articulates the reason why light therapy works to treat seasonal depression health.harvard.edu/blog/light-therapy-not-just-for-seasonal-depression-202210282840
- Get outside when it is light out: do your best to bundle up and step outdoors for at least five minutes each day. If you're able, going for a short walk in the morning can lift your mood for the rest of the day.

#### For staying indoors due to the cold:

- Take up a new hobby: Consider new indoor hobbies, like art projects, learning an instrument, or exploring a new literary genre.
- Try out new baking or cooking recipes: Check out the recipes in past issues of the PFAC newsletter! I also love the book, *Baking by Feel* by Becca Rea-Tucker. She explores the emotional elements of baking and helps people express their feelings through food!

Winter can be a difficult time in New Hampshire and Vermont, and your CF care team is here to support you. If you're feeling anxious about winter coming, please reach out to me or to Molly Stark, the social worker in Manchester. We're here to support you with both the emotional and financial impacts of winter's approach. Call 603-650-5202 or message your care team through myD-H to learn more.

# Food On The Run

Fall is underway and schedules are getting busier and busier. Whether you're running your child to practices and after school commitments or you're up to your elbows in work, the last thing on your mind is cooking a wellrounded meal for yourself or your family.

Here are a few "on the run" recipes to try, which can help that busy family (or those picky eaters):

A Month's Worth of Quick and Easy Dinners | from AllRecipes

49 Low Effort and Healthy Dinner Recipes | from eatwell101

Recipes for people with CF | from cystic-fibrosis.com

And when in doubt...
pizza and tacos
(throw in some veggies)
can be a crowd pleaser!



# Northern New England CF Foundation





### **CFF Community**

Gathering

Thank you to everyone who attended the CFF Community Gathering at Pipe Dreams Brewery in Manchester. It was a fun event and a great opportunity for our CF community to gather, connect with others and enjoy dinner while watching planes landing at the nearby airport!

