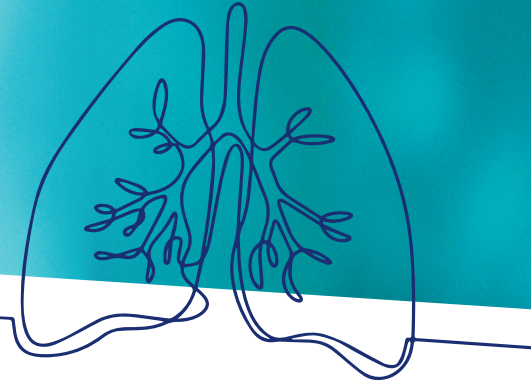


CYSTIC FIBROSIS

Patient & Family Advisory Council

DHMC CF Center



**Fall 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 nhcfpatientfam@gmail.com if you're interested in being part of this group.

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

What's inside?

- CF Community News
- Spotlight on Dr. Schroeder
- Back to School Advice
- XoC Survey Update
- CF Family Night
- and much more



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CF Community News



Congrats to the Gendreau Family on Kayla and Adams marriage!



Alyssa enjoyed participating in her musical theater group over the summer, her favorite is a song from *La La Land*.



Cadie displaying her gymnastic skills at Long Sands Beach in York, her Mom commented that she could not have done this before Trikafta!



Reid and Nadine enjoying a day on the lake #Newhampshirelife



Congrats to Logan on graduating from middle school and best of luck in high school!

Rosie enjoying salty air with her favorite dog, Nina on The Cape



Northern New England Cystic Fibrosis Consortium 2022 Continuing Education Conference

by Sarah Vooris

August 18th and 19th found members of our CF clinic team and patient/family representatives meeting with team members from the Maine and Vermont CF Centers for the 2022 Northern New England Cystic Fibrosis Consortium. The Consortium takes place to provide an opportunity to share information, developments within quality improvement projects at individual centers, and explore research topics. An ongoing effort for more than twenty years, the main goal of this collaboration is to enhance care at all three Northern New England CF Centers.



During the two day hybrid meeting, there were a variety of discipline specific sessions, discussions among subspecialty peers, investigations into select cases, and plenaries honing in on key topics facing the CF community today. Topics explored included:

**Emerging issues in women's health in people with CF
(i.e. reproductive health and changes in the era of modulator medications like Trikafta)**

**Vitamin D quality improvement projects analyzing
how increased dosage of vitamin D may help patients with low levels**

Urinary incontinence among people with cystic fibrosis

Ways to address food insecurity

Issues within the lung transplantation process

**Addressing the mental and emotional
well-being of people experiencing the
transplant process**

For more information on any of the topics listed above, connect with a member of the CF clinic team via myDH, via phone, or at your next clinic visit.



Spotlight on Dr. Scott Schroeder

New Pediatric Pulmonologist

By Sarah Vooris

Dr. Schroeder came to us from Tufts Children's Hospital 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 as he shadowed a physician working there 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.

Why did you choose to become a doctor?

I love science and I love helping people.

Why did you choose to start working with people who have cystic fibrosis? How did this come about?

The first patient I ever took care of in pediatrics was a three year old boy with CF and he was so cute, but needed a lot of support. I knew I wanted to be involved in caring for this patient and helping families affected by CF. I always say, the CF gene is next to the kindness gene.

Describe the purpose of your job to someone from another planet—an alien from outer space!

Should I speak to them in their language or in English?

How have changes in CF treatments modified how you do your job and care for patients? What has stayed the same?

It used to be that four to six times a year people with CF needed antibiotics or hospitalizations, but now with modulators, people stay out of the hospital and have a much better quality of life. The fact that there are still incredible people who take care of people with CF and their families has remained the same.



We noticed you use humor when you interact with your patients—why?

It makes my job more fun, makes for fun interactions, puts patients at ease, and allows for more honest answers.

Tell us about what inspires you in your career. What motivates you, especially on hard days?

Every day I know that I am going to do good. By seeing patients I can help them one at a time and by doing research I can help them thousands at a time.

Describe what you see as the biggest challenge facing people with CF today.

The time it takes to do their medicine and the realization that CF is no longer their whole identity.

Lightning Round

Do you play an instrument? If so, what? No

Red Sox or Yankees? Red Sox

What do you think of garden gnomes?

They're "fine" if they're properly cooked.

Sauerkraut or Mayonnaise? Sauerkraut

What was the last gift you gave someone?

Handshake to my wife for our 25th wedding anniversary.

Chess or checkers? Chess

Pogo stick or unicycle? Unicycle

What fictional character do you identify with the most? Feel free to add why, but you don't have to. You may leave us guessing. Yossarian

Pina coladas or getting caught in the rain? (kidding...kind of) Getting caught in the rain (pina coladas are too sweet)

Would you rather fight 100 duck-sized horses or one horse-sized duck? 100 duck sized horses (horses are easier to reason with)

What advice do you have for patients and caregivers transitioning from pediatric to adult care? What other transitions do you find to be most significant in the lives of your pediatric patients and their caregivers?

Transition is always hard, change is always hard, but it's inevitable. It's a period that we try to take on slowly to help children prepare to better take care of themselves as they become adults—taking on school, college, moving out, starting their own family.

Tell us about your family (two legged and four legged).

We live on a farm in NH and we have rescued numerous animals including Ziggy (alpaca), CoCo (llama), Chiclet and Chewy (miniature donkeys), and our honey bees.

What do you do for fun?

I like to box, travel, and to try hot spicy foods.

Back to school advice

Tips by CF mom Jennifer Stover

Parent/Teacher Communication: Having an open line of communication with your child's teacher is so important. We found it best to meet our daughter's teacher ahead of time, usually two weeks before school started. This allowed us the opportunity to educate them on what cf is, how it affects the body and to understand that cf affects each individual differently. Even if they'd had a child with cf in their class before, it's still important that you provide a clear picture of what your child's needs are. The CF Foundation produced a guide made just for teachers that we would bring to them at this meeting. The guidance counselor would also be present and help us create the 504 plan for the year.

504 Plan: This is a document that describes how the school will accommodate your child's special needs. Plan on updating this yearly as your child takes on more responsibility for their care. Here are some of the accommodations we found to be most helpful during the course of our daughter's school years.

Germs: We know germs are everywhere especially when small children are around. Packing hand wipes and sanitizer in your child's lunch/backpack are helpful if a bathroom isn't nearby. During the early years of school, before our daughter started to administer her own enzymes, we asked if she could take them with an adult in the school office instead of with the nurse. We were hoping to alleviate the exposure of unwanted germs/illness, since the nurse's office is typically full of sick children.

Plan ahead: We all know that a morning routine for a person with cf is already jam packed. Being able to grab a lunch that is already made, put on clothes that are already laid out and have medicine that is already packed, will help ease the morning frustration.

Privacy: Some children will not want anyone to know about their illness, while others don't mind sharing their story. Our daughter only wanted her teachers and her close friends to know. I've always felt it's important to respect whatever their decision is on this matter. There isn't a lot they can control with this illness, but who they decide to share or not share the information with should be up to them.

These are just a few things that have worked for us over the years. Every child is different. You may have your own routine that works for you, and that's great!



Back to School

Every new school year brings a mix of excitement and uncertainty. Will I like my teachers? Will my friends be in my classes? How will I perform academically? The new year also comes with so many possibilities! You may wonder how to approach these transitions with intention and optimism.

Acceptance and Commitment Therapy, which is a modality validated for use in people with cystic fibrosis, encourages individuals to identify their values and evaluate how fully they are living by them. The program prompts participants to think about work/education, leisure, relationships, and personal growth/health as the four major domains to think about. The new school year presents an opportunity to consider what your values in these domains may be, how fully you are living by these values, and how to overcome potential barriers or obstacles to doing so.

Because this exercise can take a long time and be emotionally difficult, you may consider choosing one domain to think about for now. For example, what are your values regarding work and education? How closely do you feel you are to enacting those values? What may be some potential obstacles to these values? And finally, what may you consider working on or changing in order to more closely align your actions and your values?

Whether you are a teacher, parent, student, or just an adult living in the world, September weather and shorter days can feel like the “end” to something; but it doesn't have to! Consider using this exercise as a tool to stimulate and maintain motivation going into the new school year.



As always, you can call me at 603-650-5202 or message me via MyDH for additional questions or concerns related to transitions.

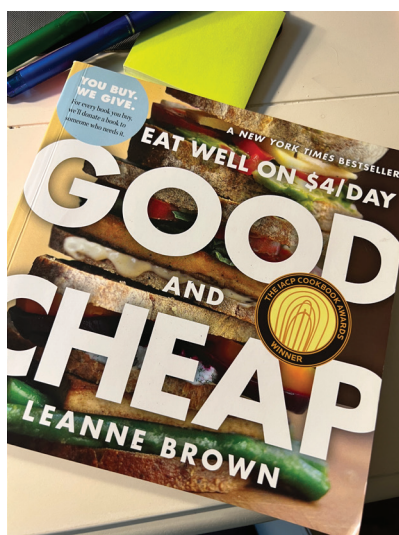
Back to School Food Tips

By Paula Garvey

We all know how hectic September can be and keeping ourselves and our families well fed and healthy can be a challenge! Here are a few tips that might help!

- Check reliable websites for ideas—my favorites are **Recipes | MyPlate** and **Back to School Recipes | Allrecipes**.
- Being organized is the key, if you shop weekly, keep a list or use an app on your phone (I use my Alexa app for our grocery list). Be aware of special offers and stock up if you can!

- Check out this book at your local library, great recipes that cost less than \$4! **All About Good and Cheap | Leanne Brown**



- Breakfast is so important, especially if you need to include fat when taking modulators.

- This omelet is perfect—quick, tasty and inexpensive **Omelet in a Mug Recipe | Allrecipes**
- Lunch should be quick and easy to make and attractive too! Sandwiches, wraps, bowls and salads all work great, I like these ideas **16 Easy School Lunch Ideas | Allrecipes** and **Taco Pinwheels—Dinner at the Zoo** Pinterest is a great resource. Also, check out, your child may qualify for free lunch!



- Snacks are essential! Homemade trail mix can be salty and high in fat and protein and low in sugar and inexpensive. I like this recipe **Kiddos Favorite Trail Mix Recipe—Food.com** Don't forget local apples and other fruits make a great snack, pair with peanut butter to add calories, fat and protein! Love these easy snacks for when the kids come in from school **Mini Deep Dish Pizzas—Damn Delicious**
- There are so many dinner options, here are a few quick and easy ideas, just google easy dinner ideas or check My Plate! Easy Dinner Recipes for Family: **90 Delicious Ideas That Will Save the Day (tasteofhome.com)** **12 Food Recipes For Kids Other Than Chicken Nuggets | McCormick**

Adding Our Voices

XoC Survey Update

by Sarah Vooris

Hello everyone! I'm Sarah, the patient/family partner serving on the new XoC, or Quality of Care, survey committee. The XoC is an updated survey developed by the CF Foundation aimed at gathering patient and family feedback with the goal of improving patient care. It is our opportunity as patients and caregivers to add our voices by sharing positives and providing insight into what may need improvement. Today, I'm reaching out to fellow families and patients to encourage you to complete the XoC surveys you receive via text message or email from the CFF.

Working alongside Jessica Skelton, Roni Finkelstein, and Emily Seamans, one of our current goals is to increase the number of patient surveys completed following clinic visits. Besides hearing about the XoC survey in this newsletter, you may also see information about it online via social media or the PFAC website. In addition, members of the CF team will mention the survey to patients/families during care visits. Expect to receive an informational flyer and mention of the survey from Kate LaMare or Emily Seamans in Manchester and Emily, Kate, or Roni Finkelstein in Lebanon.

XoC surveys are sent from the CFF and our group is looking at the collected data and sharing information from completed surveys with the entire CF clinic team. Responses are reviewed and action is taken to address concerns. All survey responses are anonymous and comments made on the surveys are included in the data received. As a side note, hearing what's good is important! Don't forget to share that, too.

Thank you to all who have completed surveys! Your voice is heard and you are making a positive change in the care patients receive at our CF Center.

A few more XoC Survey details:

Consider saving the phone number in your contacts as "Care Visit Survey—CFF" or similar. The number used by the CFF is 1-844-293-0122.

The survey is short and easy to take. It will probably take five minutes or less.

Responses are anonymous and are not linked to you or your child.

CF Center News



The 17th Annual CHaD HERO is on Sunday, October 9, 2022 in Hanover, NH and our CF Team will be walking.

Please join Team Longevity or donate following the link below. Proceeds directly support our CF team. Join our team, or donate to a team member [here](#)



Seacoast Safari, Cycle for life was a HUGE success and raised over \$140,000 to benefit the CF Foundation.

Thanks a million to the riders who participated and the volunteers who helped at the event. It was a perfect day for cycling 100 miles, 65 miles or 30 miles along the Seacoast and we saw a few familiar faces from our CF Team cycling and volunteering!



MyDH and our CF Center

How to contact the CF center

Who are the team members

What are their roles

The best way to connect with your CF Team is through MyDH. However, if you need to call here are some Important Numbers

Lebanon Pediatric CF Clinic 603-695-2745

Lebanon Adult CF Clinic 630-650-7318

Manchester, CF Clinic 603-695-2745 (option 4)

Lebanon Lab Services 603-653-3950

Manchester Lab Services 603-695-2500

CF Social Worker Lebanon, Roni Finkelstein 603-650-5202

CF Social Worker Manchester, Julie Ebel 603-695-2790

Patients should have the conversation with associate providers (GI, Endo, ENT, etc.) about how they prefer to be contacted during out of office hours.

After hours and on weekends, call the pedi or adult clinic phone number and you will be directed to the answering service who will page the on-call MD.

And remember if it is an emergency call 911

Meet the Team!

New Hampshire Cystic Fibrosis Center Team | Pulmonary Medicine | DHMC and Clinics
dartmouth-hitchcock.org

New Hampshire CF Patient & Family Education Night

Tuesday, November 15 • 5:30 pm–9:30 pm

Grappone-Marriott Center • Concord, New Hampshire

Agenda

Meet the Vendors: An opportunity to meet with pharmaceutical companies
CF Foundation, Make A Wish Foundation, Patient and Family Advisory Council

Introduction

Nicole Czyzycki RN, MSN, AE-C, CPN, Cystic Fibrosis Center Coordinator,
and Paula Garvey, Coordinator Patient and Family Advisory Council

New Team Members

CF Foundation & Compass

NACFC Updates with Dr. Julia West

Research Updates with Dr. Dan Aridgides

Registry and NH Center Update with Dr. Brian O'Sullivan

Break: Time with Vendors

Patient & Family Advisory Council

Guest Speaker – Beth Sufian (virtual)

Keynote Speaker – Gunnar Esiason

Time with Vendors

Live stream will be available

We will follow the Cystic Fibrosis Foundation's attendance policy for indoor events only one person with CF will attend

CF Foundation Northern New England News

View the latest updates from our local chapter

