

FALL NEWSLETTER

DHMC CYSTIC FIBROSIS PATIENT AND FAMILY ADVISORY COUNCIL

WELCOME TO OUR CF PFAC FALL NEWSLETTER!

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. Please email us at nhcfpatientfam@gmail.com if you are interested in being part of this group.

Mission Statement:

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.

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[NEW HAMPSHIRE CYSTIC FIBROSIS FAMILY AND FRIENDS](#)



[@NH_CF_PFAC](#)

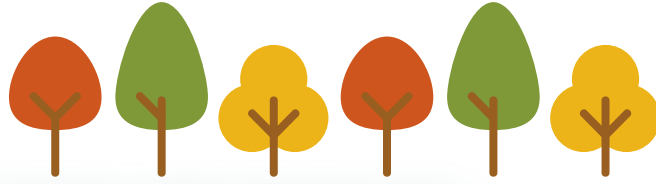


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NEWS FROM OUR DHMC CF CARE CENTER

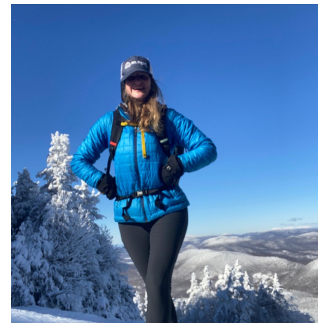


WELCOME RONI!

Hi everyone! My name is Roni and I am the new social worker on the CF team. I am moving to the Lebanon area from New York City, where I completed my MSW at NYU. I am so excited about the opportunity to meet all of you and work with this dedicated interdisciplinary team. My prior work experiences range from healthcare project management to ski instruction and wilderness guiding to oncology social work.



I am passionate about tailoring mental health support to the needs of people living with chronic and serious illnesses. As a certified yoga instructor, I integrate mindfulness and somatic awareness into my social work practice. I also look forward to learning the nuances of connecting folks with resources in New Hampshire, Vermont, and Maine. Outside of work you can find me hiking, biking, skiing, and playing with Shadow, my brother's border collie mix. I can't wait to explore the natural beauty and vibrant community in the Upper Valley.



CONGRATS TO BRIAN ON YOUR PROMOTION

Brian Bourque, PharmD, CSP joined the specialty pharmacy team in April 2018, and shortly thereafter joined the multidisciplinary CF team. In no time, his sense of humor and passion for patient care made him an incredible asset to the team. Brian was recently promoted to be a supervisor within the specialty pharmacy department, effective in early September. He has been a great patient advocate and team member for the past three years, and in true Brian fashion – his first item of business is to find the best possible pharmacist to replace him in his role in Manchester's CF clinic. We can't thank Brian enough for his contributions to our team, and know that patients and families will agree he is a fantastic pharmacist and will be missed. We have considered ourselves lucky to be part of his professional journey and can't thank him enough for all he's done for the team, patients, and families.

We wish Brian the best of luck in his new position!



SPOTLIGHT ON DR. O'SULLIVAN

BY: REGAN AND SARAH VOORIS



"The important thing is not to stop questioning. Curiosity has its own reason for existing. One cannot help but be in awe when he contemplates the mysteries of eternity, of life, of the marvelous structure of reality. It is enough if one tries merely to comprehend a little of this mystery every day."

—Albert Einstein (From the memoirs of William Miller, an editor, quoted in Life magazine, May 2, 1955; Expanded, p. 281)

Never stop questioning. As we brainstormed questions for our interview with Dr. O'Sullivan, the first mystery we aimed to comprehend seemed completely unrelated to cystic fibrosis: bowties. We were curious. Why bowties? In aiming to understand a little of this mystery, we uncovered some of what brought Dr. O'Sullivan into medicine, into the CF community, and what motivates him in his work.

"There was not a time I didn't think I would be a doctor." A curious nature, an interest in science from an early age, and a family expectation to pursue goals led Dr. O'Sullivan to pursue a career in medicine. While his Dad, who immigrated from Ireland to the US, didn't put a lot of pressure on Dr. O'Sullivan, it was expected that he would set goals and work to achieve them, making the most of available opportunities. However, Dr. O'Sullivan's journey to become a doctor wasn't a straight line.

Film study classes were Dr. O'Sullivan's favorite as a student. A stint as the director of Dartmouth's Film Society and a love for movies - especially those by Alfred Hitchcock - led to a brief professional change from medicine. While an interest in film continues for Dr. O'Sullivan, his questions and curiosity led him back to medicine, continuing with medical school at Dartmouth.

During residency at St. Christopher's Hospital for Children in Philadelphia, Pennsylvania, Dr. O'Sullivan took care of numerous kids with CF. His mentor, Dr. Dan Schidlow, was a great teacher and strengthened his interest in CF care as he trained with him to become a pediatric pulmonologist. Dr. Dan was also the first to give Dr. O'Sullivan a bowtie. If he had to wear a tie, why not a bowtie? Bowties are partially a nod to his mentor, Dr. Dan, who helped instill in him a fascination with the science of CF and a desire to care for those with the disease.

Curiosity about CF and changes in care for people with cystic fibrosis have been motivating factors throughout Dr. O'Sullivan's decades-long career. Asking questions about and comprehending some of the mysteries of the disease have led to Dr. O'Sullivan's involvement in numerous research endeavors. Blood platelet and inflammation marker research, surprising (but, unsuccessful) gene modification study, and work on medicines that deal with the underlying cause of cystic fibrosis (modulators) are a sampling of the research in which he has been involved.

Besides caring for patients directly and participation in CF related research, Dr. O'Sullivan also teaches in his role at Dartmouth as a Professor of Pediatrics and is a guest lecturer at UMass Worcester. In lectures about CF to first year medical students, he hopes to build understanding and inspire curiosity as he explains how the disruption to the cell and its CFTR protein function causes cystic fibrosis.

As a student, Dr. O'Sullivan became fascinated with the science of CF and the care of people who have cystic fibrosis. Curiosity and asking questions to uncover some of CF's mysteries began around the time Dr. O'Sullivan began wearing bowties, but the next time you see him wearing one, remember that the drive to understand continues.

A (slightly) more complicated... Lightning Round:

- Favorite book? Author? Tim O'Brien's **The Things They Carried**; Louise Erdrich
- A bit about your family? Married and has two children (a daughter and a son)
- and four grandchildren
- Salad or french fries? French fries
- The Beatles or the Beach Boys? The Beatles
- Card games or board games? Board games
- Fish or frogs? Fish
- Bowling or mini-golf? Bowling
- Lemons or limes? Limes
- Skiing or Snowshoeing? Skiing
- Pets? Cats and two Great Pyrenees dogs
- Adventures? Hiking, mountain climbing (Mt. Kilimanjaro, Mt. Rainier and others), biking and other things outdoors



CF COMMUNITY NEWS

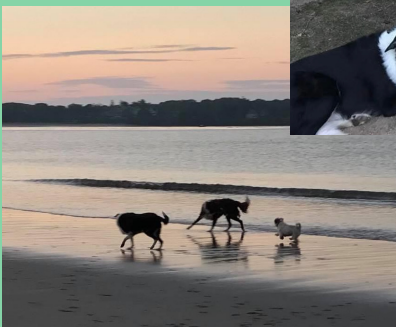
Nathan helping the community in dream job

NATHAN GENDREAU, 22, WHO CURRENTLY WORKS AS AN EMT FOR BREWSTER AMBULANCE IN NEW HAMPSHIRE, IS PICTURED HERE WITH HIS MOM, TRACY, PHYSICAL THERAPIST AT ST JOSEPH HOSPITAL IN NASHUA. NATHAN'S GOAL IN LIFE HAS ALWAYS BEEN TO BECOME A FIRE FIGHTER. HE HAS HIS CERTIFICATION FOR FF 1, AND WILL SOON BE SITTING FOR HIS ADVANCED EMT CERTIFICATION FOR THE STATE. HIS WORK AT KEEPING UP WITH TREATMENTS AND MEDS HAS ALLOWED HIM TO WORK ON PURSUIT OF HIS DREAM. HE CONTINUES TO WORK ON HIS STRENGTH AND KNOWLEDGE TO HOPEFULLY ONE DAY ATTAIN ALL HE HAS WORKED FOR IN LIFE. THANKS TO THE HARD WORK AND DEDICATION OF HIS CF CARE TEAM AND SCIENCE, HE HAS COME A LONG WAY!



Live in the moment!

Jessi loves living in the moment, her dogs are always up for anything and they make the best travel companions. Here they are playing on a beach at sunrise, at Pine Point in Maine, "I love seeing my 3 kids play together on the beach."



DHMC
CYSTIC FIBROSIS
PATIENT AND FAMILY
ADVISORY COUNCIL



REID ENJOYING THE SALTY AIR AT
HAMPTON!
EXERCISE AND SALT AIR AND
VITAMIN D, WHAT MORE COULD YOU
ASK FOR! #SALTLIFE

Why is Nebulizer Care Important?

By Jennifer Stover

- Germs can contaminate your nebulizer
- Contaminated nebulizers are a potential source of lung infection
- Cleaning and disinfecting will remove germs

CLEANING VORTEX AND AEROCHAMBERS

(Clean Weekly)

1. Remove the back rubber piece or connecting ring
2. Soak for 15 minutes in soapy warm water. Agitate gently and rinse with clean water.
3. Stand up and allow to air dry

REPLACING NEBULIZER CUPS

- The PARI nebulizer (used for TOBI, hypertonic saline and/or Pulmozyme) needs to be changed every 6 months.
- The Sidestream (used just for Pulmozyme) is also every 6 months.

STEPS FOR NEBULIZER DISINFECTION



(Disinfect after each use)

1. Designate a wash bucket to use only for nebulizer cleaning. Place in sink.
2. Spay with disinfecting spray and wait 10 minutes until sanitized.
3. Disassemble neb cups and place in wash bucket filled with soapy hot water.
4. Agitate gently
5. Rinse and place in a clean pot of boiling water.
6. Boil for 5 minutes
7. Remove from water and air dry on clean paper towels.
8. IMPORTANT: DO NOT boil masks.

Alternatives:

- Place in nebs on top rack of dishwasher-30 min.
- Place nebs in a baby bottle sterilizer on 6-8 minute steam cycle.
- Soak in 3% hydrogen peroxide for 30 minutes.
- Soak in 70-90% isopropyl alcohol for 3 min.
- Rinse using STERILE water
- Air dry

Don't forget!

Nebulizer systems such as Pari Vios and Vios Pro have filters that also need to be changed. Replace filter every 6 months or sooner if you notice your treatments taking longer than usual.



Favorite Fall Recipes

Mug Brownie

from the Stover Family

Ingredients:

- 4 Tablespoons flour
- 4 Tablespoons sugar
- 2 Tablespoons cocoa powder
- 2 Tablespoons vegetable oil
- 2 Tablespoons water
- Pinch of cinnamon

Add the sugar, flour, cocoa and salt to the mug and mix together. Stir in the oil and water. Mix well. Microwave on high for 60 seconds. Microwave times may vary (The brownie should still be wet in the center when done)

I recommend adding a scoop of ice cream and a drizzle of chocolate sauce for maximum deliciousness!

Enjoy!

Fat content = 29 grams

Calories = 460



Microwave Omelette in a Mug or Bowl

From the Vooris Family

Ingredients for 1 serving

- 2 eggs
- ¼ cup cheese - cheddar
- Vegetables: Pick one or two options from our list or your own combination.
 - ½ bell pepper, diced
 - ¼ cup fresh spinach, chopped
 - ¼ cup cherry tomatoes, cut in half or quarters
- Additional protein: Pick one or combine for ¼ cup total -cooked bacon, cooked sausage, chopped ham
- salt, and pepper to taste
- Optional: ⅓ teaspoon garlic powder or ⅓ teaspoon Italian seasoning

Steps:

- Combine all ingredients in a microwaveable mug. Make sure there is space for the egg mixture to expand as it cooks. I use a large mug or cereal bowl.
- Cook for 2-3 minutes. Check that the egg is cooked by inserting a fork or knife in the center. If it is uncooked, runny, raw egg will be on your utensil. Cooking times may vary depending on your microwave.

Enjoy! Consider adding sriracha or another favorite condiment after cooking.



**BACK TO SCHOOL SCHEDULES CAN BE BUSY,
SO HIGH CALORIE, MICROWAVABLE SNACKS AND MEALS ARE GREAT!!**

Advance Directives

By Karin Hummel

75% of Americans do not have an Advance Directive such as a living will.



ARE YOU OVER THE AGE OF 18? DID YOU KNOW IT IS RECOMMENDED THAT ALL NEW HAMPSHIRE AND VERMONT RESIDENTS OVER THE AGE OF 18 HAVE AN ADVANCE DIRECTIVE?

ADVANCE DIRECTIVE PROVIDE YOU A VOICE IN MAKING MEDICAL DECISIONS EVEN WHEN A SERIOUS ILLNESS OR INJURY PREVENT YOU FROM TALKING FOR YOURSELF; THEY ARE DIRECTIONS REGARDING YOUR FUTURE MEDICAL CARE. ADVANCED DIRECTIVES ARE EFFECTIVE SHOULD YOU BE UNABLE TO PARTICIPATE IN YOUR OWN MEDICAL CARE.

ADVANCED DIRECTIVES ARE LEGAL DOCUMENTS THAT STATE WHO YOUR DURABLE POWER OF ATTORNEY FOR HEALTHCARE WOULD BE; THIS IS ALSO CALLED A HEALTHCARE AGENT. YOU LIKELY HAVE AN EMERGENCY CONTACT LISTED IN YOUR MEDICAL RECORDS, HOWEVER THERE ARE LAWS SURROUNDING WHO COULD BE YOUR HEALTHCARE AGENT AND FOR HOW LONG SHOULD YOU NOT HAVE AN ADVANCED DIRECTIVE.

IT IS IMPORTANT AND HIGHLY RECOMMENDED THAT YOU COMPLETE AN ADVANCED DIRECTIVE. THEY CAN TAKE TIME TO COMPLETE. THE INFORMATION IS IMPORTANT TO HAVE DOCUMENTED IN THIS LEGAL FORMAT IN ORDER TO ENSURE YOUR WISHES ARE DOCUMENTED AND THE PERSON YOU TRUST IS YOUR VOICE IN THE EVENT OF A HEALTHCARE EMERGENCY.

**TO GET MORE INFORMATION OR TO COMPLETE AN ADVANCED DIRECTIVE GO TO:
NEW HAMPSHIRE: WWW.HEALTHYNH.ORG
VERMONT: WWW.VTETHICSNETWORK.ORG**



At Home Spirometry

BY SARAH VOORIS AND KATE LAMARE

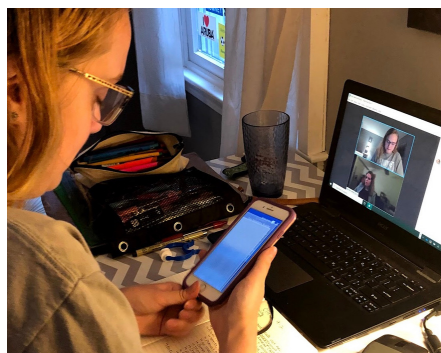
IN RESPONSE TO THE COVID-19 PANDEMIC, MANY PEOPLE WITH CYSTIC FIBROSIS BOTH IN THE US AND INTERNATIONALLY USED HOME SPIROMETRY DEVICES FOR THE FIRST TIME. CREATED TO MONITOR AND SHARE LUNG FUNCTION, HOME SPIROMETERS PROVIDE USEFUL DATA ON LUNG HEALTH TO PATIENTS AND CF TEAM MEMBERS. THE DEVICES HELP PATIENTS AND CAREGIVERS AVOID HEALTHCARE SETTINGS AT CRITICAL TIMES IN THE PANDEMIC WHILE STILL HAVING THE BENEFIT OF TRACKING LUNG HEALTH.

SPIROMETRY TESTS ARE A TOOL USUALLY USED IN THE HEALTHCARE SETTING - IN A PFT LAB OR A CLINIC EXAM ROOM. THESE TESTS SUPPLY DATA ON THE PROGRESSION OF CF IN THE LUNGS AND HELP MAKE IMPORTANT DECISIONS ON TREATMENTS. WITH THE ADDITION OF HOME SPIROMETRY DEVICES, TESTS CAN BE DONE AT HOME WITH INFORMATION SUPPLIED TO THE CF CLINIC TEAM ELECTRONICALLY. PEOPLE WITH CF CAN BETTER MONITOR THEIR OWN HEALTH WHILE ALSO PROVIDING VALUABLE DATA TO THEIR CF CARE PROVIDERS.

AS CONDITIONS WITH THE PANDEMIC CONTINUE TO EVOLVE, HOME SPIROMETER DATA ADDS TO INFORMATION COLLECTED AT CF CLINIC VISITS. IT IS ANOTHER TOOL, LIKE BLOODWORK, PHYSICAL EXAMS, OR X-RAYS, THAT HELPS GET A BETTER PICTURE OF PATIENT HEALTH. ALL HEALTH INFORMATION GATHERED IS CONSIDERED WHEN MAKING DECISIONS ABOUT CARE. BEFORE SCHEDULED CLINIC VISITS AND WHEN THERE ARE HEALTH CONCERNS ARE TWO TIMES DURING WHICH HOME SPIROMETRY WILL BE USED. USING THE DEVICE BEFORE COMING TO CF CLINIC HELPS REDUCE TIME IN THE HEALTHCARE SETTING.

THE CF TEAM WILL WORK WITH EACH PATIENT TO CREATE THE BEST PLAN FOR USE OF HOME SPIROMETRY. QUESTIONS ABOUT ANY TEST RESULTS SHOULD BE DIRECTED TO YOUR PULMONOLOGIST. YOUR CLINIC RESPIRATORY THERAPIST IS ALSO AVAILABLE TO ADDRESS QUESTIONS ON USING THE HOME SPIROMETRY DEVICE AND PERFORMING THE TESTS.

**PLEASE CONTACT KATE LAMARE AT (603)650-7972) OR
KATIE.E.LAMARE@HITCHCOCK.ORG**



BE HEARD.

MAKE A

DIFFERENCE.



CYSTIC FIBROSIS FOUNDATION

What is Community Voice?

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

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

LEARN about Foundation programs and research through exclusive updates.

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

HOW IT WORKS

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

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

- Marieliz, Community Voice Member



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

**CYSTIC FIBROSIS FOUNDATION
NORTHERN NEW ENGLAND CHAPTER**

UPCOMING EVENTS

GREAT STRIDES CYSTIC FIBROSIS FOUNDATION



**Fall Great Strides Walks! Mark your calendars for
Saturday, September 18th at 9am!**

**Our Fall walks will be celebrated with a virtual
event this year. After our celebration online, we
encourage you to safely "Stride Your Way" by
walking or doing some other activity you love!**

**Burlington Great Strides: Sunday, September 19th
Bar Harbor Great Strides: Saturday, September 18th
Belfast Great Strides: Saturday, September 25th**



**Join us for Swing for CF October, 4th 2021
at Breakfast Hill Golf course!**



**Virtual Taste for a Cure
Huge online auction Nov 4th -7th,
just in time for holiday shopping!
Stay tuned...**

<https://events.cff.org/tasteforacurenh>



**CYSTIC FIBROSIS
FOUNDATION®**

September is Self Care Awareness Month!

Treat yourself today!

Self-Care Reminders

1. Be really kind to yourself.
2. Say "yes" to meeting a need.
3. Pay attention to how you talk to yourself.
4. Pause and take really deep belly breaths.
5. Cheer yourself on.
6. Be gentle with your feelings.
7. Do one thing that makes you really happy.
8. Love yourself the best you can.

DHMC CYSTIC FIBROSIS
PATIENT FAMILY ADVISORY COUNCIL

PERSPECTIVE PARTNERSHIP DHMC CF PFAC

CHECK US OUT		
 @nh_cf_pfac	 New Hampshire Cystic Fibrosis Family and Friends	 @nh_cf_pfac

AS PATIENTS, FAMILY MEMBERS, CAREGIVERS, AND CF CLINIC STAFF, WE EACH VIEW CF FROM A DIFFERENT ANGLE. THE DHMC CYSTIC FIBROSIS PATIENT FAMILY ADVISORY COUNCIL BRINGS PEOPLE TOGETHER ACROSS OUR CF COMMUNITY TO ADD THEIR PERSPECTIVES, TEAMING UP TO ENHANCE PATIENT CARE AND QUALITY OF LIFE.

Consider sharing your unique perspective with the DHMC CF PFAC. Options include, but are not limited to, participating in a short term project, sharing your ideas for a newsletter article, and joining PFAC long-term. Interested in getting involved? Email Paula at: nhcfpatientfam@gmail.com.

