



SPRING 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. Check out the "Meet The PFAC" in this issue! 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.

We will serve as a coordinating mechanism for patients and families, and promote improved communication and relationships between patients/families and CF Center staff.

Follow us on Social Media

 [New Hampshire Cystic Fibrosis Family and Friends](#)

 [@nh_cf_pfac](#)

 [@nh_cf_pfac](#)

**May is CF
awareness month!**

In this Issue...

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- What are your hobbies?
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- News from The CF Foundation, Northern New England Chapter

News from your DHMC CF Team

What does your CF team do at the weekend?

Recently, our amazing CF Center team has been busy at the weekends ensuring that Granite Staters and Vermonters got their Covid vaccines! Thanks to Dr Guill, Dr. O'Sullivan, Dr. West, Dana Dorman, Emily Dutille, Nicki Felicetti, Karin Hummel and Beth Labarge for helping get shots in arms! Emily got to vaccinate her grandparents! See if you can recognise our superheroes behind the masks! if you need to sign up for a vaccine appointment in NH call 211 and in VT call 1-855-722-7878.



PFAC and CHaD are working on a project to help patients feel prepared for their admission experience. Torie Miele (child life specialist) has been collecting feedback from families and adult patients on their hospital stays to add input to create an admissions handbook. Please reach out to Torie if you are interested in providing your feedback. She is reachable by email Victoria.miele@hitchcock.org or phone: (603) 650-0226

*We need
your input!*

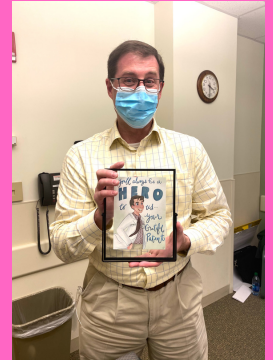
*Thank
you!*

THANK YOU to all RESEARCH PARTICIPANTS from the Research Team.
Without your selfless volunteering,
we would not have the medications and therapies that we do!

**May is CF
awareness month!**

Good Luck Dr. Gifford!

Dr. Alex Gifford moved to NH with his family in 2003, where he completed his residency and Critical Care/Pulmonary fellowship at DHMC. He developed a passion for caring for patients with CF under the mentorship of Dr. Worth Parker, and the rest is history! He has cared for many, many CF patients (and their families) for over a decade, both in Lebanon and Manchester and has helped many patients through the transplant process. He is so loved by patients and team members alike, that when he shared the news that he and his family were moving to Cleveland, Ohio, it was met with both sadness and joy for his next chapter. We wish him all the very best in his new adventures and are thrilled that he will continue to share his expertise and passion with those living with CF in Ohio.



Welcome!

Welcome to new CF Team member Laurie Stadler. Laurie will be joining the team as CF research nurse.

Fun fact about Laurie - Laurie got her motorcycle license 3 years ago and now rides her Harley every chance she gets.

Life with cystic fibrosis can be challenging at times, but help is available. Please reach out to your CF clinic social workers for support, resources, or if you have questions.

Julie Ebel - Julie.A.Ebel@hitchcock.org

Karin Hummel - Karin.B.Hummel@hitchcock.org (603) 650-5202

General Resources:

New Hampshire: www.211nh.org or call 211

Vermont: www.vermont211.org or call 211

211 provides information on programs and services available that are provided by local community groups, social service and health-related agencies, government organizations, and others in New Hampshire or Vermont.

Food Resources:

New Hampshire: nhfoodbank.org Vermont: vtfoodbank.org

Need food tab-agency list

Programs-mobile food pantry

Do you need support?
Help is here!

LETTER FROM DHMC CYSTIC FIBROSIS CENTER TEAM

May 1, 2021

A number of changes in CF team personnel have recently happened or will be coming soon, and we wanted to let you know about all of them with one letter.

Dr. Alex Gifford is leaving in mid-May to take a new position in Cleveland, OH. Dr. Gifford has been a valued member of the CF care team for more than 10 years and has served in many roles. He will leave big shoes to be filled and we will miss him. Dr. Julia West is stepping into the role of Interim Adult CF Program Director and Dr.

Rick Enelow will continue to work with the Center as an adult physician. A new adult CF physician will be recruited, however, the CF team is committed to continuing the high quality of care that our patients expect.

We welcomed Laurie Stadler in April as a new CF research nurse. Many of you may know her from her former role helping to transition CF patients from the hospital to home IV treatment. Laurie is an experienced nurse who is eager to learn the ropes in CF research and has jumped right into the program.

Karin Hummel, our adult and pediatric social worker in Lebanon and CF Center Mental Health Coordinator, will be leaving us at the end of June to move to the DC area. We will miss her sorely but wish her well in the move. Again, recruitment is already under way for a replacement.

Dr. Lou Guill is retiring at the end of June. She has been Pediatric Program Director and Interim CF Center Director, roles that will be assumed by Dr. Brian O'Sullivan. Dr. O'Sullivan will continue seeing pediatric CF patients in Lebanon, along with gastroenterologist Dr. Julie Sanville. He will continue working with our two nurse practitioners in Manchester, Julie Houchell (pulmonology) and Danielle Cantin (gastroenterology) to manage the CF patients in the southern part of the state.

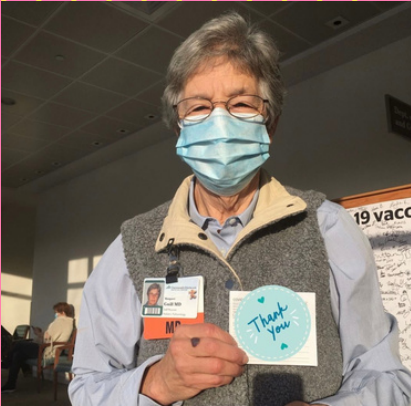
And finally, as we prepare for Lynn Feenan to move into retirement within the next year, we would like to introduce a new approach to the Center Coordinator role—it will take three people to replace Lynn and the work she is doing. Nicki Felicetti will continue as the Adult Program Coordinator, discussions are under way regarding the best fit for the Pediatric Program Coordinator, and these two nurses will share the role of CF Center Coordinator with Emily Dutille, our Specialty Pharmacist in Lebanon. We will continue to keep you apprised of the status as this evolves.

We know this is a lot to digest and any team member is available to talk to you about this more if you have questions.

Your New Hampshire Cystic Fibrosis Center Team

Spotlight on Dr. Lou Guill

By S, J, and MJ Vooris



Listen to the Mustn'ts

**Listen to the MUSTN'TS, child,
Listen to the DON'TS
Listen to the SHOULDN'TS
The IMPOSSIBLES, the WON'TS
Listen to the NEVER HAVES
Then listen close to me -
Anything can happen, child,
ANYTHING can be.**

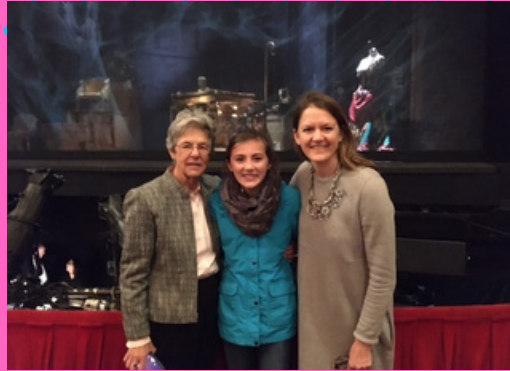


Shel Silverstein, Where the Sidewalk Ends

Our family first met Dr. Margaret "Lou" Guill when we moved to VT in 2009. She had recently started at DHMC as a pediatric pulmonologist in the CF Clinic. We had only been a part of the CF community for one year with the diagnosis of our newborn daughter in 2008. The "mustn'ts, shouldn'ts, never haves, impossibles and won'ts" conflicted easily in our heads with hope and possibility. Thinking that "anything can be" was a struggle, the future uncertain. Dr. Guill's wealth of experience, pragmatic approach, and focus on relationships was invaluable.

Dr. Guill has been a doctor for nearly fifty years. Growing up in the suburbs of Atlanta, GA, science, history, sports (like swimming), and literature were favorites. Inspired by a book series about a nurse named Cherry Ames, she originally wanted to be one, but later decided to become a doctor. Graduation from the Medical College of Georgia was followed by time at Kaiser Permanente Medical Center in California. Her training and work as a general pediatrician and allergy specific medical doctor preceded her role as a doctor for patients with cystic fibrosis. When the CF doctor left while she was working in Georgia, Dr. Guill took their place. She really liked it and continued in that role until "retiring" from the Medical College of Georgia after a thirty year career as a provider, researcher, and teacher.

Over time, Dr. Guill's role as provider, researcher, and teacher has evolved with developments in patient care. Having been at the conference during which Dr. Frances Collins announced the identification of the CF gene to being part of trials for Pulmozyme, inhaled Tobramycin, CF modulator medicines and more, Dr. Guill witnessed "never haves, impossibles, and won'ts" turning into hope and possibility. Dr. Guill stated, "With asthma and CF the environment of care has changed and improved. There are much better outcomes for patients, better lifestyles." Over time she has also transitioned from doing a lot of inpatient/outpatient work to more outpatient care. Throughout all of these changes Dr. Guill's emphasis on relationships with others remained paramount.

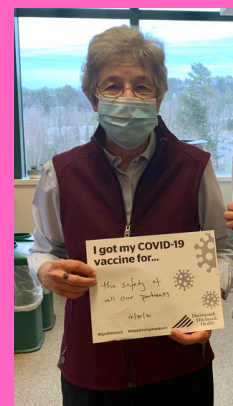
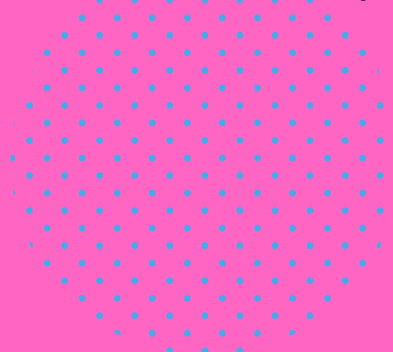


What's it like seeing patients grow and change? "It's rewarding. Seeing the patient and family change over time is similar to observing children and grandchildren grow up." Developing relationships, being at high school graduations and weddings of patients are some of Dr. Guill's favorite memories as she gets ready to embark on her life's next chapter - official retirement. Dr. Guill wants to be remembered as a "happy and positive person who enjoys life and experiencing it" and in retirement will be doing just that as she spends time with family, including her seven grandkids - ages 14 to five months. Reading, long walks, and travel will also be part of the plan. We wish you well and thank you for your role in helping us to enjoy and experience more of life and to not only see the "mustn'ts, shouldn'ts, never haves, impossibles and won'ts," but also see the hope and possibility. "Anything can be."

Did you know? Dr. Guill has traveled to a lot of countries! She's traveled for vacation and to do medical work and research in Peru, Ecuador, El Salvador, Tanzania, and more.

Lightning Round:

- Cats or dogs - Dogs
- Favorite food? All of it
- Winter or summer - Summer
- Favorite book? Becoming by Michelle Obama; Shel Silverstein (anything), Goodnight Moon
- Desert or ocean/beach - Ocean
- Favorite dessert? Pecan pie
- Dark or milk chocolate - Dark chocolate
- Swimming or riding bikes - Swimming
- Bungee jumping or skydiving - Neither
- Favorite color? Blue



MEET YOUR PFAC

JACK BURNHAM

I am a part of the Patients and Families Advisory Council because I think that patients should be involved in shaping their care and that everyone's voice should be heard in medicine.

Fun fact: I ran the Covered Bridges Half Marathon at 13.



NICOLE CLUFF

I'm on the board to work with patients and families to find ways to improve the lives of our families in creative ways. Working with the board makes me a better nurse by learning from the true experts

Fun fact: I had a career in radio before becoming a nurse. If you had insomnia, you could hear me on the overnights at WZLX in Boston.



LYNN FEENAN

I am part of this group because I fundamentally and deeply believe that patients and parents HAVE to be part of the CF Team for us to provide the best possible care to our patients.

Fun fact: I have a new "COVID puppy" named Penny. "She is a complete character who has brought a lot of joy to her family in the midst of this crazy time."



PAULA GARVEY

I'm on the council as I believe that the CF community has so much to offer each other. My daughter has Cf and I would like to share my experience as a parent and learn from others in the Cf Community.

Fun fact: I sat beside Bono once at a traffic light!



ROSIE GARVEY

I'm in PFAC because, as an adult living with cystic fibrosis, I think my perspective could be valuable.

Fun fact: I know all the words to the musical Hamilton



TRACY GENDREAU

I joined PFAC because I enjoy being involved in the CF network, learning new things, and meeting other CF parents and family members..it takes a village!

Fun fact: I would rather be quilting or outdoors on the water any day of the week!



LOU GUILL

PFAC is a link between the care team and patients/families outside the setting of the care experience itself. This is an important venue for communication unrelated to individual patient care and for getting patient and family input into the big picture

Fun fact: I was a competitive swimmer in high school and college.



KARIN HUMMEL

I am on the board because it is exciting to have a new way to connect patients, families, caregivers, and team members in order to collaborate on new ways to maintain and improve the quality of care and education given to CF care.

Fun fact: I have lived in seven states.



KATE LAMARE

I'm the adult and pediatric respiratory therapist, I joined the PFAC because a partnership with patients and families improves performance.

Fun fact: I'm an avid chicken farmer. Here I am caring for an injured hen, Torchic; Pokémon reference because my husband and daughter are big fans!



DENISE MCCLOAT

Teacher, wife, and mother of three kids. I am part of PFAC because I want to stay on top of all the great things the center is and has done for our CF community, and do what I can to help continue this amazing work! My daughter's fight with CF has inspired me to never take anything for granted and never give up hope.

Fun fact: I played soccer from the age of four to age 17 as a goal keeper.



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awareness month!**



TORIE MIELE

I joined PFAC to continue my child life work of strengthening the voices of patients and families and help make positive changes for the best patient experience.

Fun fact: My favorite color is yellow and I love snowboarding, stand up paddle boarding, and hiking.



KELSEY PRENDERGAST

I'm on the board because I have a four year old daughter with cf.

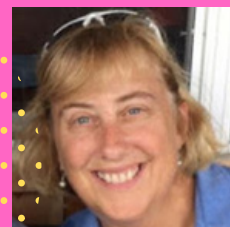
Fun fact: I played soccer and basketball in college.



KATHY SABADOSA

I am a PFAC member to contribute my lived experience as a parent of an adult with CF and help the DHMC CF community thrive!

Fun fact: I know how to ride a camel.



JENNIFER STOVER

I wanted to be a member of PFAC, so I could collaborate with the health care team that cares for my daughter. Having the opportunity to provide feedback regarding our family's experience and care is so important to me.

Fun fact: I used to babysit for a former Boston Bruins hockey player.



HANNAH VIGEANT

I'm so excited to be a part of this group and being able to give teens with CF a voice.

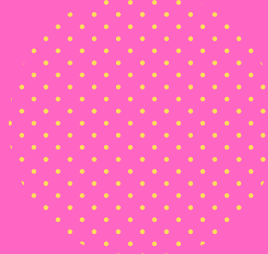
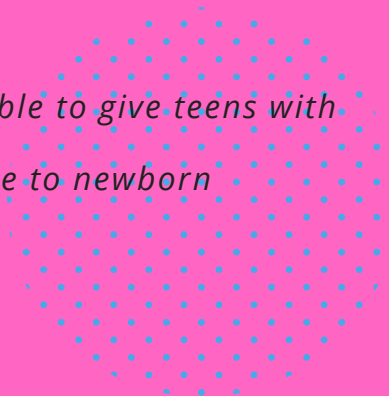
Fun fact: I was the first baby with CF found in NH due to newborn screening.



SARAH VOORIS

I am part of PFAC as I am the mom of two girls living with cystic fibrosis.

Fun fact: My girls' interest in rock climbing led me to take up the sport about four years ago. It quickly became a favorite for me as well and is now an activity we do together.



Respiratory Therapy Tips for Adults

"I do morning treatments first thing in the morning to feel productive and either watching tv or playing a game while doing treatments, which sometimes includes longer sessions to continue playing. In the evenings, I usually watch sports while doing treatments, which I find works well with my schedule."
Jack - adult with CF



"I do my VEST and nebs first thing in the morning (unless I have an early class/work) before I start my day so I don't keep pushing them off and so I feel productive right off the bat. I tell myself I can play video games or watch TV for the duration of my nebs before I start my schoolwork (this sometimes leads to me doing extra Vest so I can keep playing). I leave them out (I know this not always possible) so I am constantly reminded and it is easy to just sit down and do them"
Rosie - adult with CF

"Studies suggest adherence is best when positive expiratory pressure (PEP) and flutter devices are used. If you're in a serious relationship, teach your significant other about your treatments they can help with. Be motivated by reality. Do what you do today for all those tomorrows."
Kate - Respiratory Therapist

Nathan's treatments are currently once a day (yay!!) He does them on his computer or gaming system, something to engage him. His gear is on a rolling cart from Ikea that fits the Vest perfectly, so if he wants to watch the Bruins with his dad he just rolls them to the living room! He does his treatments at night, as his job had him out the door at 3.30 AM, so he figured he would do them before bed at 700. He said he can't do any reading while on the vest...too much shaking and it makes him seasick!
Nathan - adult with CF

Staying busy! Show 'n Tell.

*CF
in real life!*

Life with cystic fibrosis can be demanding, so it is really important to find time to relax and enjoy your favorite hobby. Spending time on an activity that you enjoy can improve your mental health and wellbeing. Research shows that people with hobbies are less likely to suffer from stress, low mood, and depression. Activities that get you out and about can make you feel happier and more relaxed. And we all know that physical activity is really important for lung health too!

Do you have a hobby you LOVE? Please share pictures so we can share with our CF Community.

Painting is something that Abby has enjoyed for years. It's her form of "therapy" for a stressful day.



Hannah is a competitive Cheerleader!



Reid is an avid Skier!

Cadie loves to grow succulent plants!



Avery loves skiing in Vermont!



**May is
Cystic
Fibrosis
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*CF Community
News*

SAUSAGE AND SPINACH ALFREDO



SPINACH IS A RICH
SOURCE OF IRON!!

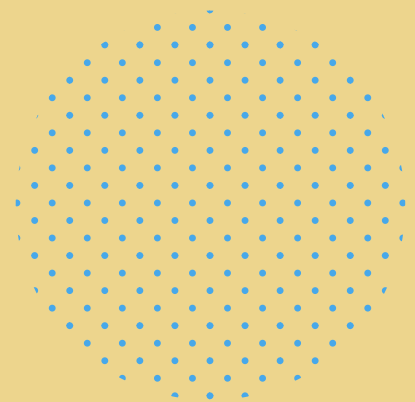
This family favorite recipe was shared by PFAC member, Jennifer Stover

Ingredients

- 1 package of ground sausage
- 1 cup chopped onion
- 1 tablespoon minced garlic
- ½ cup chicken broth
- ½ pound fettuccine, cooked, drained
- 2 cups whipping cream
- 1 cup grated Parmesan cheese
- 1 bag (6 ounces) baby spinach leaves (stems removed)
- 1 package of fettuccine noodles
- Black pepper to taste

Directions

1. Cook sausage, onion, and garlic over medium heat for 8-10 minutes or until sausage is thoroughly cooked. Drain. Return sausage mixture to pan.
2. Stir in chicken broth. Bring to a boil. Reduce heat to medium; cook 4-5 minutes.
3. Cook the fettuccine according to directions on the package.
4. Add pasta, cream and cheese; bring just to a boil, stirring constantly. Cook and stir for 4-5 minutes or until cheese is melted and sauce is thickened. Remove from heat.
5. Stir in spinach; cover. Let stand 3 minutes. Season with pepper.
- 6 Enjoy!



Let's get moving in May

GET READY FOR GREAT STRIDES WITH TIPS FROM PFAC MEMBER AND CF MOM, KELSEY PRENDERGAST!

MAY

CHOOSE A FORM OF CARDIO APPROPRIATE FOR YOUR FITNESS LEVEL TO COMPLETE TWICE A WEEK ON DAYS YOU CAN GET OUTSIDE OR ON SOME INDOOR EXERCISE EQUIPMENT.

	SUN	MON	TUE	WED	THU	FRI	SAT
Cardio Ideas:			3 rounds: 10 squats 10 crunches 10 jumping jacks		5 rounds: 20 lunges 5 push-ups *45 sec rest*		
walk			3 rounds: 10 burpees 5 squat jumps 30 sec plank		3 rounds: 10 squats 10 crunches 10 jumping jacks		
run			5 rounds: 20 lunges 5 push-ups *45 sec rest*		3 rounds: 10 burpees 5 squat jumps 30 sec plank		
hike			3 rounds: 10 squats 10 crunches 10 jumping jacks		5 rounds: 20 lunges 5 push-ups *45 sec rest*		
bike							
elliptical							
row							
stair climber							

EXERCISE IS GREAT FOR YOUR LUNGS, HEART AND MENTAL HEALTH!

THESE WORKOUTS FOR THE MONTH OF MAY CAN BE MADE AS EASY OR AS HARD AS IS APPROPRIATE FOR YOUR FITNESS LEVEL AND EXPERIENCE. EVERYTHING CAN BE DONE WITH ZERO EQUIPMENT UNLESS YOU'RE FEELING STRONG AND WOULD LIKE TO HOLD SOME WEIGHT FOR SQUATS AND/OR LUNGES. PUSH UPS CAN BE MODIFIED TO BE DONE AGAINST A WALL, WITH HANDS UP ON A CHAIR OR STEP OR FROM THE KNEES ON THE FLOOR. BURPEES AND PLANKS CAN ALSO BE MODIFIED TO BE DONE FROM A RAISED PLATFORM FOR THE ARMS IF YOU'RE NOT COMFORTABLE GOING ALL THE WAY TO THE FLOOR.

IF YOU'RE JUST STARTING OUT ON YOUR FITNESS/WORKOUT JOURNEY, AN ACCOUNTABILITY BUDDY CAN BE EXTREMELY HELPFUL. EVEN IN THE DAYS OF COVID, YOU CAN STILL HAVE AN ACCOUNTABILITY BUDDY THAT ISN'T PRESENT AT THE MOMENT OF THE WORKOUT, BUT THAT DOES THE SAME WORKOUT PROGRAM AND CHECKS IN TO SEE IF YOU COMPLETED IT, WHAT YOUR PLAN IS FOR THE DAY OR HOW YOU'RE FEELING. SO FIND A BUDDY AND SOME TIME IN MAY TO GET MOVING FOR HEALTH SAKE!



Kelsey Prendergast graduated from Plymouth State with a BA in exercise science. She worked as a personal trainer at The Executive Health and Sports Center in Manchester, NH before opening CrossFit Wachusett with her husband in Fitchburg, MA. After eight years of owning a business and having their first child, Avery (now four years old and has cystic fibrosis), they moved to VT. Before continuing her coaching and personal training career at The Body Lab in VT, Kelsey had a second child, Calvin (now one year old and is a cystic fibrosis gene carrier). Once the pandemic hit, Kelsey went completely virtual with her coaching and personal training, doing everything via Zoom with her two small assistant coaches. She is also currently working on a Sport and Exercise Nutrition Certification.

Check out CFF Community Voice

A great resource for all in the CF Community



BE HEARD.

MAKE A

DIFFERENCE.

What is Community Voice?

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

PARTNER with the Foundation, researchers, and other organizations. We can't be successful without your input.

LEARN about Foundation programs and research through exclusive updates. Gain an insider perspective on projects.

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

HOW IT WORKS

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

“We won't know what is important to everyone, until we hear from everyone.”

- MARY, COMMUNITY VOICE MEMBER

Join Today: cff.org/CommunityVoice

News from the Cystic Fibrosis Foundation NNE

CYSTIC FIBROSIS FOUNDATION
NORTHERN NEW ENGLAND CHAPTER

UPCOMING EVENTS



Join us for our next virtual CFF Cares on Tuesday, May 25th at 7pm. As a family member or friend of someone living with CF, we invite you to join and connect with others! RSVP by May 24th to receive the link: northern-newengland@cff.org.



GREAT STRIDES® Great Strides provides opportunities for all people within a local community to get involved forming teams with friends, family and colleagues. Our spring walks will be celebrated virtually on May 15th! For more information: greatstrides.cff.org.



CYCLE FOR LIFE® Please join us virtually on July 17, 2021 as we celebrate Cycle for Life together – it will be a moment you won't want to miss! <http://fightcf.cff.org/seacoastsafari>

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NEWSLETTER TEAM

PAULA GARVEY, KARIN HUMMEL, KELSEY PRENDERGAST,
JEN STOVER, AND SARAH VOORIS.
IF YOU HAVE IDEAS FOR FUTURE NEWSLETTERS,
PLEASE EMAIL
NHCFPATIENTFAM@GMAIL.COM