

WELCOME TO

DHMC CF PATIENT AND FAMILY ADVISORY BOARD WINTER NEWSLETTER

What is CF PFAB?

PFAB is a group of patients and families who live with cystic fibrosis, and members of the the CF care team. We meet every two months.

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

Our Mission

The DHMC CF Patient and Family Advisory Board seeks to enhance the care and quality of life of the CF population. We aim to connect CF patients, family members, and the CF center team to identify ways to improve the daily lives of people living with CF and their families.

Follow us on Social Media



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



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LATEST NEWS FROM THE DHMC CF TEAM

Research at DHMC

Did you know that we have an active CF Research Department at DHMC which engages in research spanning from observational to pharmaceutical? The Cystic Fibrosis Research Department also gathers patient samples for use in bench (basic) research by the Lung Biology Group at Dartmouth College. This research is used to enhance current diagnoses and therapies with the goal to ultimately discover new therapies, devices, or cures. If you have a question about research, please feel free to contact Dana, Leah or Barb.

Leah.K.McGinley@hitchcock.org

Barbara.A.Rodgers@hitchcock.org (Lebanon)

Dana.B.Dorman@hitchcock.org (Manchester)

DHMC CF Pharmacy Department

Supported by funding from the CF Foundation, our CF center pharmacists now have pillboxes available during your next clinic visit. Smaller boxes with multiple sections are perfect for pancreatic enzymes or other medications on-the-go. Split into morning and evening, the weekly pillbox is large enough for multiple tablets and capsules (yes, even vitamins!).

If you are interested in bringing one of these home, ask a CF team member at your next clinic visit.

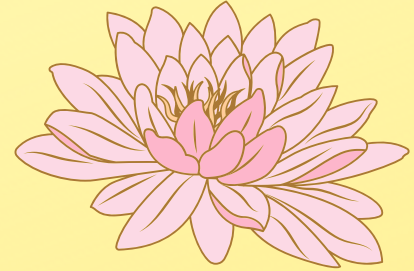


Social Work

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

If you need to connect with a mental health counselor, visit www.psychologytoday.com for detailed listings of professionals available near you.

Suicide Hotline available 24/7 at 800-273-8255.

Cystic Fibrosis Foundation

Northern New England Chapter News

2021 Event Calendar

2/27/2021	CF MiniCon: Transplant
3/11/2021	Virtual Ski for The Cure
3/16/2021	CF Fighter Social Hour
4/15/2021	ResearchCon 2021
4/20/2021	CF Foundation Cares
5/15/2021	Virtual Great Strides
7/17/2021	CF Cycle for Life
TBD	Grampions

114 Perimeter Rd Units G&H Nashua, NH 03063
Phone: 800-757-0203 Email: no-new-eng@cff.org

SPOTLIGHT ON: LYNN FEENAN

CF Team Spotlight: Lynn Feenan RN, MSN - CF Center Nurse

By: MJ Vooris (age 9 with CF) and Sarah Vooris



Growing up in Bennington, VT, Lynn's childhood wasn't quite like that of many kids today. No internet, no cell phones, but four siblings to play outside with and loads of pie making with her Grandmother. A good key lime pie? Fresh blueberry pie with vanilla ice cream (warm out of the oven)? Coconut cream? Lynn finds it hard to choose today, but it wasn't pie that set the idea of being a nurse in her mind. It was popcorn.

Burns on her hand and foot that occurred while making popcorn for her little brother sent Lynn to the hospital for treatment at the age of fifteen. She was hospitalized for a month. With her mother recovering from an illness and her best friend having moved away, it was a lonely and difficult time. A few excellent nurses made a huge difference for Lynn while in the hospital. "I think I want to be a person like that for other people," she thought. 42 years later Lynn says it's one of the best decisions she's made in her life.

Albert, Carrie, Zoe, Sarah. Early in her career, Lynn Feenan fell in love with kids who had cystic fibrosis, setting her on a path that found her always learning, passionately advocating, and working hard for those in the CF community. When Lynn started as a nurse, things for kids with CF were different. Available enzymes didn't work well. There were few medicines and no vest systems for airway clearance. There was a lack of knowledge about how people with CF could share harmful lung bacteria with each other.

Before it was discovered that going to CF camp was a potentially dangerous situation, Lynn enjoyed going to camp. The experience of spending a week in the woods doing all sorts of camp activities with kids with cystic fibrosis is one of her favorite memories. It gave Lynn perspective about day to day life with the disease. She now talks to families all the time about how to fit CF care into their lives and also continues to learn something new from them everyday.

The development of all kinds of new medicines for CF care has changed the lives of people with CF. It has also changed Lynn's role as a nurse. In her words, "It's stunning to watch all the new medicines come out." Challenges often arise with new care options. When Lynn first started her career, if a patient needed a medicine, they got the medicine. Today, planning ahead, understanding what insurance companies pay for and knowing which pharmacies provide the medicines is a big part of her job. It makes Lynn angry and frustrated sometimes, but it also makes her absolutely sure she "will fight the fight for my patients" and not stop advocating.

Elements of Lynn's career evolved in other ways over the years, too. When she first started, she was the only CF nurse for kids and adults. Support was limited. Now there is a much bigger team. The expansion of the CF care team, along with more help from the CF Foundation, has changed Lynn's job as a nurse for the better. Annual two day CF retreats that include the entire CF care team (Lebanon and Manchester) as well as patients and families focus on improvement of care. It is a "time to sit and decide together how to work smarter and better - to be better" and one of Lynn's fondest memories.

Reflection seems to come more often lately as Lynn looks ahead to retiring in 2022. Albert, Carrie, Zoe, Sarah. Early in her career, Lynn fell in love with kids who had cystic fibrosis. Since, she has fallen in love with many more. May the hundreds of lives she has impacted for the better take her passion and move forward with it, picking up where she leaves off - always learning, teaching others, and working hard to make things better for those in the CF community. Thank you, Lynn!

The Lightning Round: A Lighter Spin on Interviewing

- Spaghetti and Meatballs or Pizza? Spaghetti and Meatballs
- Chocolate or vanilla? Chocolate cake and vanilla ice cream
- Coffee or tea? Tea
- Sweet or sour? Sweet
- Summer or winter? Summer, but I love snow.
- Dogs or cats? Dogs
- Book or movie? Movie (I love going to the movies, going to the theater)
- Flowers or trees? Flowers
- Gryffindor or Ravenclaw? Gryffindor
- Mountains or Beach? Mountains
- Superpower? To fly!

PFAB's Favorite Winter Recipe

We are very aware of the importance of calories and good nutrition in the CF diet. Below is a favorite recipe suitable for those looking to add some extra calories into their diet. Enjoy!

ONE-SKILLET CHICKEN THIGHS WITH BUTTERNUT-SQUASH



Shared by: Kelsey Prendergast

Serves: 4-6

Ingredients:

- 1/2 lb bacon
- 6 whole boneless skinless chicken thighs
- 2 1/2 cup butternut squash, cubed for frying
- 1 bunch sage, chopped
- Salt and pepper

BUTTERNUT SQUASH IS
A GOOD SOURCE OF
VITAMINS A AND C

Directions

- Preheat oven to 425 degrees F.
- In a large skillet, over medium heat, fry bacon until crispy. Set bacon aside & crumble when cooled.
- In the same skillet, sauté cubed butternut squash in bacon grease until soft. Season with salt & pepper.
- Once squash is soft, remove from skillet & place on a plate.
- Add chicken thighs, top down in the skillet & cook for 10 minutes.
- Lightly season the thighs with salt & pepper. Flip the thighs over, then add squash back into the skillet.
- Remove the skillet from the stove top & place in your preheated oven.
- Bake in oven for 12-15 minutes until chicken is cooked through.
- Carefully remove from oven, top with crumbled bacon & fresh sage. Serve!

Winter Fun Activity Challenge



Complete 10 of these activities to be entered in an Amazon gift card raffle.

- | | | | |
|--|--|--|--|
| <input type="checkbox"/> Go sledding | <input type="checkbox"/> Go snowshoeing | <input type="checkbox"/> Make snow angels | <input type="checkbox"/> <u>Look for animal tracks</u> |
| <input type="checkbox"/> Build a snowman | <input type="checkbox"/> Take a winter walk | <input type="checkbox"/> Help shovel | <input type="checkbox"/> <u>Winter scavenger hunt</u> |
| <input type="checkbox"/> Go ice skating | <input type="checkbox"/> Paint the snow | <input type="checkbox"/> Take a night walk | <input type="checkbox"/> <u>Make a healthy snack</u> |
| <input type="checkbox"/> Build a snow fort | <input type="checkbox"/> Throw snowballs | <input type="checkbox"/> Go skiing | <input type="checkbox"/> Play flag football |
| <input type="checkbox"/> Homemade ice sculptures | <input type="checkbox"/> <u>Paper snowflakes</u> | <input type="checkbox"/> Play flashlight tag | <input type="checkbox"/> <u>Freezing bubbles</u>
*if temp is below freezing |

Let us know when you've finished!
Email us at nhcfpatientfam@gmail.com
to be entered in the raffle.

We would love photos that we can share on social media!



THE INS AND OUTS OF CYSTIC FIBROSIS: HANDS-ON CF LEARNING KITS

MINDBLOWN!



Designed by CF
mom, Sarah,
and child life
specialist, Torie



MindBlown Kits provide a fun and engaging opportunity to learn about how CF affects the body and what treatments can do to help. Each kit includes hands-on activities to teach about a specific body system so kids (and adults!) can learn about how the body works. A collaboration between Sarah Vooris (mom to children with CF) and child life specialist Torie Miele, the kits aim to explore science concepts, connect them to CF care, and put it all together to increase understanding for patients and caregivers within the CF community and beyond.

Each kit has all supplies needed to make that set of projects. Some supplies (like scissors or tape) are meant to be used for multiple kits. Kits are grant funded and free! The first two kits focus on the respiratory system and germs. Future kit content will include the gastrointestinal system and nutrition, kidneys and blood filtration, the immune system, genetics and heredity, and more.

KIT AVAILABILITY

Who: Developed for kids 7-13 years of age

When/Where: CF clinic appointments in Lebanon or Manchester, inpatient stays, or by mail anytime by request

How: Connect with your child life specialist directly or via your CF care team.

"Tricks of the Trade"

Respiratory Treatments

By: Kate Lamare,
CF Respiratory Therapist



Ages 2-8

- Laughs are a good "treatment"; play a silly game.
- Fill a clean bin with water and bubbles. Using a straw, encourage your child to blow out as many bubbles as possible.
- Find a sport they love. Use this time to observe what motivates your child. Positive reinforcement? Gifts? Discipline?

Ages 9-12

- Mix it up. Your child doesn't want to combine their free time with treatments? Then integrate their treatments with homework.
- Consider a reward system, such as a compliance chart.

Ages 13-16

- You and your child should begin transitioning to treatment independence with minimal supervision.
- Sign your teen up for a gym membership (but sanitize any equipment they use).
- Experiment with different breathing exercises and tools. Ask your respiratory therapist for recommendations.

Ages 17 and beyond

- You should be completely independent by now.
- If you're in a serious relationship, teach your significant other about the treatments they can help you with.
- Do what you do today for all those tomorrows.

REMEMBER....

- Don't attach reward systems to PFTs – the patient can feel like a failure if they have low lung function.
- Check x-rays to know which spots need focused CPT.
- Nebulizers have a nasty taste? Suck on a mint while doing them.
- Whenever contemplating not doing your treatments, say "I'm choosing not to do my treatments because my health is not a priority"; shift your focus.



"Tricks of the Trade"

Respiratory Treatment Ideas from PFAB

During treatments, try one (or more!) of the ideas below:

- Play games - board games, video games, solitary games
- Read - gather a stack of books and enjoy story time during their treatment session.
- Listen to an audiobook or podcast - borrow audiobooks from your local library. Using headphones or earbuds will make it easier to hear over the machine noise.
- Listen to music - create playlists of your favorite music that are timed to stop for huff coughs.
- Save screen time for treatments - kids will jump into their vests if they know they can watch their favorite show or movie.
- Create Art - Use crayons, paints, stickers, feathers etc. There are many tutorials online to help with drawing or craft ideas.
- Construct with building toys.
- Use play dough!



***I can
&
I will***



Other things to consider:

- Keep the vest in the main living area of your house, so your child does treatments amongst family and friends. Being there to monitor them ensures they are doing their treatments properly.
- Get organized. Setting up a cart that keeps the vest and supplies accessible and all in one place will help things run smoothly.
- Think about the timing and adjust if necessary. Too tired and cranky? Be flexible with timing!
- Make the vest portable. Take it outside or to a friend's house.
- Try to stay flexible - what worked yesterday may not work today. There will be times that your child pushes back.
- Reach out if you're feeling overwhelmed. You have the support of your family, friends, doctors, nurses, clinicians and the CF Foundation.

MEET THE TEAM



Providers



DR. MARGARET "LOU" GULL

*Interim Director, DHMC CF Center
Co-Director, Pediatric CF Program. Ped Lebanon*

Fun Fact: Dr. Guill was a competitive swimmer in high school and college.



DR. BRIAN O'SULLIVAN

Co-Director of the Pediatric CF Program, Ped Manch

Fun Fact: Dr. O'Sullivan ran the Dartmouth Film Society for one year after graduating from college and almost went to graduate school for cinema studies rather than to medical school!



JULIE HOUNCHELL

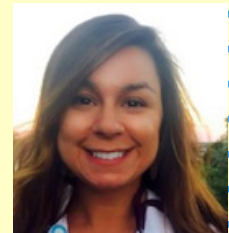
Nurse Practitioner, Pediatric CF Program Lebanon

Fun Fact: Julie is a certified family nurse practitioner who works with the pediatric CF team, but has been known to help in the young adult group too.

DR. JULIE SANVILLE

Pediatric Gastroenterologist, Leb

Fun fact: She is a paw mom to a one-year-old chocolate lab named Jonas and a 16-year-old cat named GreyGoose.



DR. ALEX GIFFORD

Director of the Adult CF Program, Manch and Lebanon

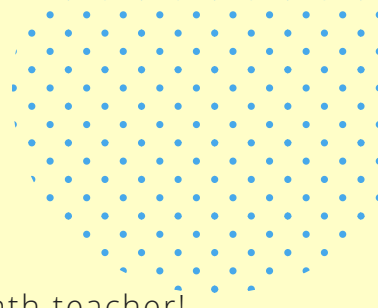
Fun Fact: Dr. Gifford grew up on a Christmas tree farm and raises his own spruce and pine trees.



DR. JULIA WEST

*Pulmonary & Critical Care Physician Lebanon
Adult and transition patients*

Fun Fact: Before becoming a doctor, Dr. West was a math teacher!



DR. RICHARD ENELOW

Physician, Adult CF Team Lebanon

Fun fact: Richard's favorite food is Red beans and rice from the Napoleon House, French Quarter, New Orleans!



DANIELLE CANTIN

ARNP Ped GI Manchester

Danielle had breakfast with Barack Obama on the day she graduated with her bachelor's degree.

TONY PLANTE

Physician Assistant, Adult Gastroenterology Manchester

Fun Fact: Tony is an avid hiker in all seasons. The picture (at right) was taken from the top of Mount Monroe. The towers of Mount Washington are in the background.



Nurses



LYNN FEENAN

Nurse Coordinator for the NH CF Center

Fun Fact: Lynn has 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."



NICOLA (NICKI) FELICETTI

Adult Coordinator for the NH CF Center

Fun Fact: Nicki completed the NH 48 x 4000 footers (mountains)!



NICOLE CLUFF

Nurse, Southern Pediatric Center Coordinator, Manchester

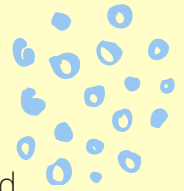
Fun Fact: Nicole had a career in radio before becoming a nurse. If you had insomnia, you could hear her on the overnights at WZLX in Boston.



BETH LABARGE

RN, Pediatric Pulmonary Clinic, Lebanon

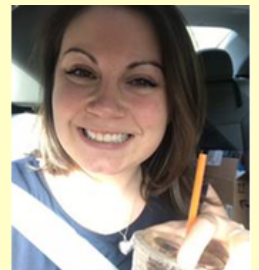
Fun Fact: Beth petted a dolphin and squealed like a three-year-old.



JESSICA SKELTON

Pediatric CF Nurse, Manchester

Fun Fact: Jessica has a caffeine and Amazon obsession!



MARY WOOD

Diabetes Clinical Nurse Specialist, Lebanon

Fun Fact: Mary and her husband have an old Volkswagon bus and recently went to Colorado, via Missouri and Kansas. She has been to all 50 states.

Social Work



KARIN HUMMEL

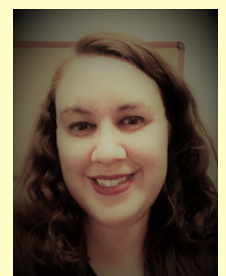
Social Worker and Mental Health Coordinator, Lebanon

Fun Fact: Karin has lived in 7 states.

JULIE EBEL

Pediatric Specialties Social Worker, Manchester

Fun Fact: Julie has a mini dachshund and cat that enjoy scheming together to knock the butter dish off the counter to share a snack.



Child Life



TORIE MIELE

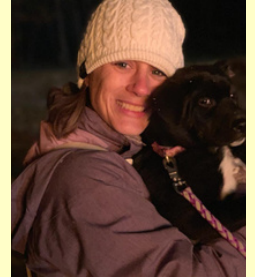
Outpatient Child Life Specialist, Lebanon

Fun Fact: Prior to being a child life specialist she worked with an organization called Paws and Affection to help train pediatric service and facility dogs. Her pup pictured here (Totie Joy) is a “drop out” from the diabetes alert program.

SONYA CHARLES

Outpatient Child Life Specialist, Manchester

Fun Fact: The pup pictured with Sonya is one she fostered and then never left.



NICOLE R. NOELTING

Inpatient Child Life Specialist, Lebanon

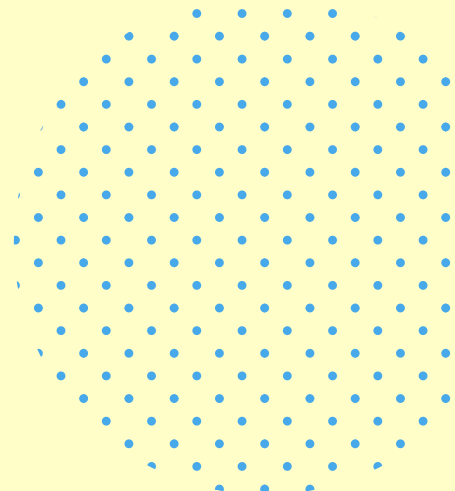
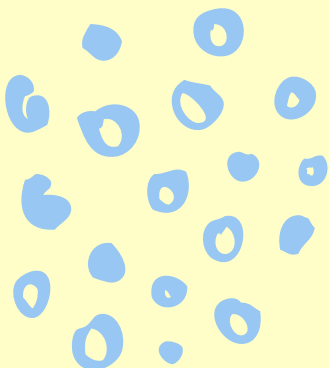
Fun Fact: She shares her birthday with her puppy, Mila, and they both have blue eyes.

Respiratory therapy

KATIE LAMARE

Respiratory Care Practitioner Lebanon

Fun Fact: Katie is a US Master Swimmer and HS swim team coach.



Nutrition

LAURIE CAMPBELL

Adult and Pediatric Team Nutritionist, Manchester

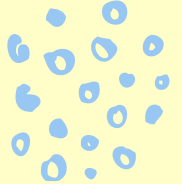
Fun Fact: Laurie owns a bag collection.



EMILY COOPER

Adult Clinical Dietitian/Nutritionist Lebanon

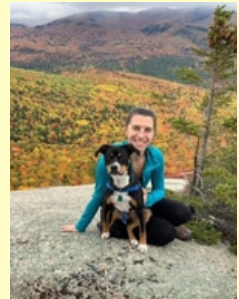
Fun Fact: Emily hopes to go to culinary school one day!



ALEX DEBOW

Adult CF Team Dietician, Lebanon

Fun Fact: Alex loves to hike with her dog Kofi.



CATHERINE (CAT) GIGUERE-RICH

Pediatric CF Team Dietician, Lebanon

Fun Fact: Cat grew up on a dairy farm and her high school job was milking cows.

Pharmacy



EMILY DUTILLE

Clinical Specialty Pharmacist, Lebanon

Fun Fact: "My husband and I love to explore the U.S. National Parks – we've been to 36 out of 62, and hope to visit the others soon!"

BRIAN BOURQUE

Pharmacist Manchester

Fun Fact: Brian studied abroad at the University of Saint Andrews in Scotland and played golf eight days per week on the Old Course.





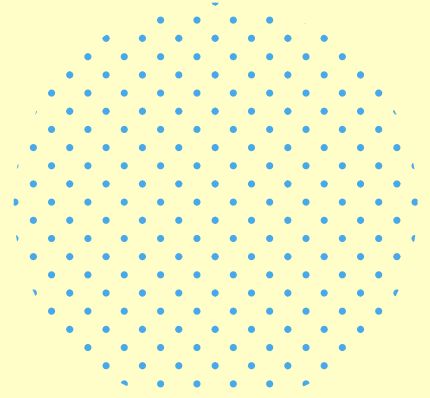
KARA CRONIN

Pharmacy Technician Lebanon

Fun Fact: She went to Hawaii for the very first time in January, 2019 and she hopes to go back someday!



Research



DANA DORMAN

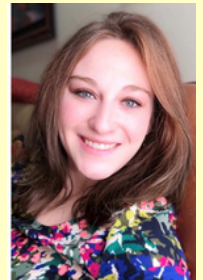
CF Research Nurse, Manchester

Fun Fact: Dana wanted to be a dolphin trainer, but hated the smell of fish. She also would never share her chocolate with them to foster behavior reinforcement!

LEAH MCGINLEY

Pharmacy Technician

Fun Fact : Leah loves being active and spending time outdoors. She was an alpine racer growing up. Leah loves mountain biking and taking her dog on hikes.



BARBARA RODGERS

Research Team Study Coordinator Lebanon

Fun Fact: Barb fell asleep while riding on the back of a motorcycle. "An hour long ride, never fell off, and didn't wake until the engine shut off!"

This newsletter was brought to you by DHMC PFAB

Newsletter Team

Paula Garvey, Karin Hummel, Kelsey Prendergast, Jen Stover, and Sarah Vooris.

Your PFAB members: Jack Burnham, Nicole Cluff, Lynn Feenan, Paula Garvey, Rosie Garvey, Tracy Gendreau, Lou Guill, Karin Hummel, Kate LaMare, Denise McCloat, Torie Miele, Kelsey Prendergast, Kathy Sabadosa, Ashley Shortt , Jessica Skelton, Jen Stover and Sarah Vooris