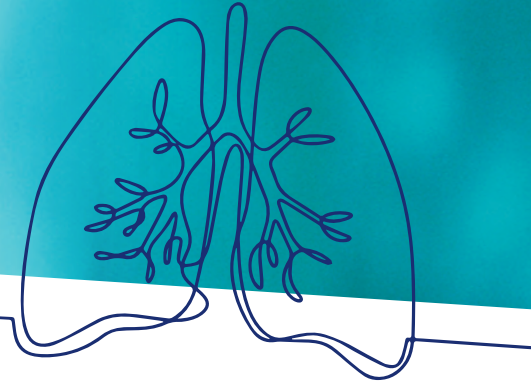


CYSTIC FIBROSIS

Patient & Family Advisory Council

DHMC CF Center



Summer 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: Emily Seamans, Roni I. Finkelstein, Paula Garvey, Kristin McCarthy, Ashlee Robinson and Sarah Vooris

What's inside?

Spotlight on
Mary Ellen Corliss

Advocacy Update

Traveling with CF

Great Strides Recap

and much more



Follow
Us



CF Community News

School Information Session

Second grader, Caroline, and nurse Nicole hosted a CF information session with Caroline's class to educate her friends about life with CF. If you would like Nicole to visit your class, please connect with her! Thank you Nicole and Caroline for your advocacy!



College Graduation News

Congrats to Tovah Duffaut, from Raymond NH. Tovah graduated with a major in English and a minor in anthropology from Colby College. She was chosen by the senior class to deliver the student address at commencement on May 21st. Tovah also served as a sexual violence prevention peer educator as well as a co-mentor for the Office of Access and Disability Services. Well done Tovah!

Boston Marathon
Well done Kerri on completing your 3rd Boston Marathon!

And this time in the rain.



Local Author has Book signing event!

A very special author was escorted by police to the Barnes and Noble store in Manchester for her first book signing.

Elyse Beaudette, 10, of Nashua, recently published her first book, *Corgi of Justice*. Elyse was recently surprised by Make-a-Wish NH when they published the book for her. *Corgi of Justice* is available now at Barnes and Noble and through several [online retailers](#).



CF Vests Worldwide

Do you have a vest or other equipment you no longer use? An amazing non-profit organization, CF Vests Worldwide, provides vests and other medical equipment to CF patients worldwide who cannot access them.

Check out this link for more details

CF Center News

Northern New England CF Consortium Meeting

In March the CF teams from the University of Vermont Medical Center, Maine Health and Dartmouth Hitchcock Medical Center gathered in Burlington, VT for NNECF. This annual meeting gives our team an opportunity to connect, collaborate and discuss happenings in other CF centers and learn about CF topics. This year's topics included an interesting presentation on stem cell research by Dr. Dan Weiss (UVM) and a presentation on the management of early lung disease by Dr. Stephanie Davis (UNC Children's Research Institute). If you have any questions about these discussions please contact your team.



Welcome to Molly Stark

Our new Social Worker for Pediatric Specialties at DHMC Manchester

Molly loves backpacking and hiking. She spends most of her weekends wandering through the mountains and appreciating trees.

New Hampshire CF Patient and Family Education Night

Mark your calendars for **Wednesday, November 15**. Family Education Night is our chance to catch up on all the latest local and national CF information and listen to our keynote speaker, Nicholas Kelly. You can join us live at the Grappone Center in Concord or virtually—details to follow!

Mark your calendars

**NH CF PATIENT AND
FAMILY EDUCATION
NIGHT
WEDNESDAY
NOV 15TH 23**

keynote speaker



**NICHOLAS
KELLY—**

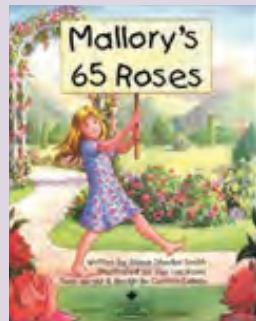
nhcfpac.com

Summer Book Review

Mallory's 65 Roses
By: Diane Shader Smith
(written in 1997)

**Recommended ages:
2–5 years old**

Mallory's 65 Roses is a playful book following a young girl named Mallory through her everyday life with CF. This book explores Mallory's daily treatments, "tune up" hospitalizations, and GI enzymes, all in a short direct manner of a young child. This book is a bit dated in its discussion of treatments (no vest treatments back in the 90s!), but mentions a basic young child's understanding of her illness, her brother's experience, and Mallory's big feelings about living with a chronic illness. All in all, a great book for young kids to start their understanding of their body and CF and help remind us of how far our research and treatments have come.



Review by: Torie, Child Life Specialist

If you are interested in reading and reviewing a book about cystic fibrosis for the PFAC newsletter, reach out to Torie or Sonya from child life at your next clinic visit. Check with your CF team for other books that have been generously donated to PFAC for our patients and families. The purchase of these books was made possible by the Cystic Fibrosis Foundation.

Spotlight on Mary Ellen Corliss



Why did you become a nurse? What is your favorite thing about being a nurse?

I love caring for and helping people. I became a nurse later in life, getting my RN in 2002 at the ripe old age of 34!

How has your job changed over the years?

I worked for 18 years in hospice as a nurse, clinical manager and director. After 18 years of a lot of travel and time away from family I needed a change. I found the position as Adult CF Coordinator here at DH.

How long have you worked at Dartmouth?

In different roles, a total of nearly 12 years!

Why did you become a nurse for people with CF?

I was looking for something different. I wanted to learn more, but didn't want to go back to school (no more student loans!). I found the Adult CF Coordinator position and it intrigued me because I went to school with two brothers who passed away in the 80's from CF. I wanted to learn more about the advances made in treatment since that time.

Tell us about some of the challenges and joy you've experienced so far in your career.

Challenges...

Well, I think getting through the pandemic was the biggest. It changed the way I had to provide care as a nurse.

Joy...

Every day I get to help and support people who are dealing with a chronic illness. If I can make one person's day easier by listening, supporting, guiding...that brings me joy!

Where did you grow up? What were some of your favorite subjects in school and activities?

I was born in Connecticut and moved to NH when I was 10 years old. I spent most of my time as a child in West Unity, NH and went to school in Claremont, NH. I LOVED US History! It was my favorite class. I was an avid reader and could spend a whole day reading.

What are some of your hobbies or interests?

I am a “junk journaler.” I make journals from everyday items, like homemade papers, etc. It’s peaceful and creative. I love the outdoors and going on picnics or long drives with my husband, Craig.

What do you want your patients to know about you? Both teens coming soon to the adult CF clinic and adults already receiving care at our center?

I am here to support them in any way! If I can’t answer the question, I will find out who can. I am an ear when you are feeling overwhelmed and just need to talk or some reassurance. I am always open to helping with anything.



Lightning Round

Matching or mismatched socks?

Mismatched = “Happy Feet”

Are you someone who likes things that are sweet and cute? If so, what is something that has made you go “awwww” recently?

I am a total dog lover.

Any dog makes me go aww.

Cookies or cake?

Both

Would you rather team up with Captain Marvel or Wonder Woman?

Wonder Woman

Swim in a pool of nutella or maple syrup?

Ewwwww. If I had to choose, I would pick maple syrup (the real stuff!)

Happy or sad songs?

Both! Depends on my mood.

Sweet or sour?

Sweet!

Book or Kindle?

Kindle (for the convenience), but cookbooks in book form.

Advocacy Update

May 2023

During the CF Foundation's annual March on the Hill event March 8th and 9th, volunteers from the CF community advocated for the PASTEUR Act and the HELP Copays Act. More than 175 advocates urged members of congress to cosponsor and pass these two bipartisan pieces of legislation. 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.

Advocacy for the passage of the PASTEUR and HELP Copays Acts continues as we work to get members of congress to cosponsor the bills. With more congressional cosponsors, PASTEUR and HELP Copays have a greater chance of becoming 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 members of congress.

Thank you to Kathy, Kelly, Rachel, Rebecca, Sarah, and Tim for advocating on behalf of the CF community in Maine, New Hampshire and Vermont!



For more information on March on the Hill, check visit: cff.org/news/2023-03/advocates-urge-action-16th-moh

Community Feedback

Communicate more with your CF team using the XoC Survey

By Sarah Vooris

XoC Team - Patient/Family Representative

Getting feedback from the CF community served by our CF clinic team in Lebanon and Manchester is key to adding the perspective of patients and families to make change and support practices that work for us (and don't) in the clinic setting. As CF patients and caregivers, we can talk to team members at clinic visits and over myDH. But, sometimes we forget to mention something important to us, it comes to us hours after we had our appointments, or we feel more comfortable sharing in writing than in person about topics of concern.

The XoC survey from the CF Foundation (sent to you via text after a clinic visit) is a great tool to communicate more with the CF team. Our XoC survey team looks at all the data and comments, later sharing them with other team members. We are listening to what the CF community served at DHMC has to say and are using it to help guide change. Please consider adding your voice by completing the XoC survey the next time it is sent to you. Your feedback matters!

▶▶ A few XoC Facts:

A post-visit survey that is short and easy to take

Anonymous, the survey is not linked to patient names or birthdates

Survey link comes via text message (from 1-844-293-0122) the week following your clinic visit to the number you supplied to the CF team.



Traveling with CF

When living with CF, travel needs extra planning. As summer approaches we asked our local CF patients, families and our care team to share any tips they have on making traveling a little easier.

Talk with your medical team early about your travel plans so they can help provide medical advice and extra prescriptions if needed for your trip.

Consider asking the clinic team for documentation that confirms your medical need for the medicine and equipment. This can be helpful going through airport security, customs, etc.

If traveling abroad, check electrical power ratings at your destination and bring suitable adapters and transformers for equipment.

Leave extra time for TSA when flying. One mom suggested "It is well worth the money to get TSA precheck! Much quicker and less anxiety producing when traveling"

The TSA toll-free helpline is 1-855-787-2227. You can also visit the TSA online at [TSA.gov](https://www.tsa.gov).

Buy carry on bags for the vest so it is easier to get through security and fit in the overhead bin. Also, take the equipment to the store when purchasing the bag to make sure it fits.

Use bags of frozen peas to keep meds cold.

Board early with the first group that needs extra time in order to stow your vest and cooler in overhead bins.

Make a master packing list that includes medications and other CF related supplies.

As always, don't forget your hand sanitizer and wash hands frequently.

Pack plenty of snacks and water for car rides.

Don't leave enzymes in a hot car.



The Summer Schedule: to Plan or not to Plan?

As the weather warms up and the school year comes to a close, many families foresee an ocean of unstructured time during the summer. This change in schedule is both a challenge and an opportunity. Unstructured time is important for child development—it's an opportunity for creative play and boosting confidence. Yet a lack of routine can also cause increasing depression and anxiety in both children and adults. Creating a weekly calendar may enable you to make intentional decisions about how to spend your time this summer. Here are a few ideas for how to create routine during the summer, while still encouraging creative play. These ideas are for both children and adults!

- 1.** Write down a list of goals for the summer: Is there a project you've been meaning to work on? Do you enjoy reading and feel like you don't have enough time during the year to finish books? Think of a SMART (specific, measurable, achievable, relevant, and time-bound) goal that you would like to accomplish in the summer months. You may also like to schedule a time during each day to work toward this goal.
- 2.** Research local hiking trails: schedule hikes into your weekly schedule! I really like the AllTrails app to find local trails. Don't forget to bring sun protection, wear long pants and socks, and check for ticks after.
- 3.** Schedule time with friends: Maybe you'd enjoy meeting up with the same friend once each week for lunch or for a dog walk. Making these social connections is imperative for mental health!
- 4.** Find an accountability buddy: If you worry that you'll have trouble meeting your goals or struggle with motivation to schedule your time intentionally, consider finding another person with a similar summer schedule. You may enjoy reporting back to someone about all the cool things you're doing with your time.



GREAT STRIDES

CYSTIC FIBROSIS FOUNDATION



LEBANON | NASHUA | RUTLAND

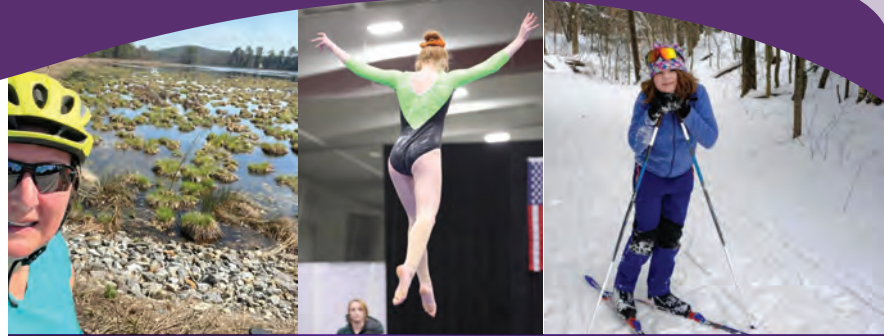


WALK-O-RAMA

What started off as a discussion on how to encourage our CF community to be more active and ultimately enjoy better health, turned out to be an amazing, fun event! We had marathon runners, cross country runners, gymnasts, skiers, bikers, walkers and more participate in our first ever CF Walk-o-Rama. A total of 30 people registered, and in a relatively small CF center, that is a good participation rate. Over the months of March and April, each participant tracked their activity and submitted their weekly step or distance totals. Participants who submitted steps/distance totals were entered into a weekly prize drawing.

We rocked! Over the course of eight weeks of Walk-o-Rama participants walked a total 6,821,532 steps, totalling over 3,000 miles (3,035 to be exact). Despite the New England spring weather the average number of steps stayed strong, with the weekly average around 10,000 steps. Our top stepper, Fran, totaled 851,693 steps! Congratulations to all of the teams, but especially the legendary Joshua's Angels who walked a total of 2,343,536 steps. Pretty Amazing!

On completion of Walk-o-Rama we surveyed our participants and here's what we learned.



Select the statement that best describes you:

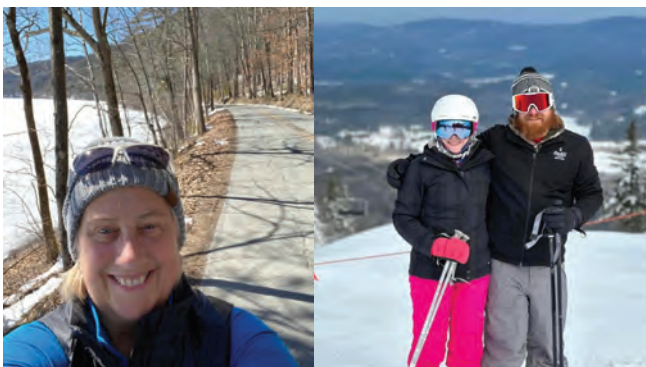
- 37.5% I was a committed walker/runner, absolutely love getting on the treadmill or out on the road before Walk-o-rama and now I have moved to never missing a day.
- 37.5% I was a casual fitness walker/runner, perhaps as training for another activity or sport when I started Walkorama and I increased my training.
- 25.0% I had some previous experience exercising regularly before Walkorama and I have increased my exercise routine.

Walkorama changed my current exercise habits:

- 12.5% Strongly agree
- 50.0% Agree
- 37.5% Neutral

On a scale of 0-10, how likely are you to participate in an event like Walkorama next year?

100% 10



Revised CF Nutritional Guidelines

By Cat Giguere-Rich

Nutritional Considerations for a New Era, a CF Foundation position paper on potential nutritional changes in the era of highly-effective modulator therapies (HEMT) like Trikafta was published this week. Our pediatric nutritionist, Cat Giguere-Rich shares some key points from this important paper. There is additional research that needs to be done, but there are some small changes we can share with the continued goal of keeping people with CF healthy and happy!

- 1.** The traditional high fat, high calorie CF diet may have negative nutritional consequences for some people with CF as they age (especially long term heart health). It may be more appropriate for some to encourage healthy foods (fruits, vegetables, lean proteins, low fat dairy, whole grains, and legumes) and physical activity, which can support maintaining a healthy weight and cardiovascular health.
- 2.** It is recommended we move away from the traditional use of BMI for nutritional status in CF. An individualized approach (involving all medical team members) may be more helpful in supporting our patients to reach their nutritional goals (including healthy body image).
- 3.** Food insecurity screening should still be part of the standard of care in CF.
- 4.** There is a lack of data to make specific recommendations about salt intake, monitor blood pressure at each visit.
- 5.** Further studies are needed to better understand the effect of HEMT on the need for pancreatic enzymes. Checking a fecal elastase after starting HEMT in children up to age 5 may be helpful. Check fecal elastase in other age groups based on clinical judgment.

This is a great article and I look forward to us getting closer to clear evidence based guidelines. It will not be a one size fits all it seems. I completely agree with the individualized approach to nutrition care.

“It is clear that since the introduction of HEMT, we are in the midst of a rapidly changing nutrition world for our CF patients.”

Healthy Food Choices

By Paula Garvey

Life with cystic fibrosis has always been complicated and now in the era of modulators, patients and families are aware that for some of us dietary needs have changed and we need to “rewire” old habits. Some patients need a high calorie diet, others do not. Some of us need high fat in the morning, others need high sodium/salt. And as people with CF are living longer and healthier lives, the community is now dealing with health conditions such as colon cancer, heart disease, and other aging-related issues. Diet and food decisions play a very important role in staying healthy. At the moment the advice is to follow the Mediterranean diet.

Here is some information from the Mayo Clinic:

What is the Mediterranean diet?

The Mediterranean diet is a way of eating that’s based on the traditional cuisines of Greece, Italy and other countries that border the Mediterranean Sea. Plant-based foods such as whole grains, vegetables, legumes, fruits, nuts, seeds, herbs, and spices are the foundation of the diet. Olive oil is the main source of added fat. Fish, seafood, dairy and poultry are included in moderation. Red meat and sweets are eaten only occasionally.



Healthy fats instead of unhealthy ones

Olive oil is the primary source of added fat in the Mediterranean diet. Olive oil provides monounsaturated fat, which lowers total cholesterol and low-density lipoprotein (or “bad”) cholesterol levels. Nuts and seeds also contain monounsaturated fat. Fatty fish, such as mackerel, herring, sardines, albacore tuna and salmon, are rich in omega-3 fatty acids. These polyunsaturated fats help fight inflammation in the body. Omega-3 fatty acids also help decrease triglycerides, reduce blood clotting, and lower the risk of stroke and heart failure.

Here are some tips

- Build meals around vegetables, beans and whole grains.
- Eat fish at least twice a week.
- Use olive oil instead of butter in preparing food.
- Serve fresh fruit for dessert.

Living the Mediterranean way also means being physically active and sharing meals with loved ones!

Northern New England CF Foundation

SEACOAST SAFARI CYCLE FOR LIFE July 15

Registration is open for the 100 mile, 65 mile and 30 mile cycle!

NEW THIS YEAR: A 0:0 "Run." Join the fun with no exertion!
The 0.0 Run registration is at 12 pm and the start is at 1 pm.

*We are looking for volunteers to help with registration, set up and SAG Vehicles.
Contact northern-newengland@cff.org if you can help!

Register: fightcf.cff.org/seacoastsafari

REGISTRATION
FOR THIS
YEAR'S 0.0
"RACE" WILL BE
\$25/PERSON

WITH THE
OPTION TO
FUNDRAISE FOR
PRIZES!

With registration each
runner will receive:

- Official Race Number Bib
- Live Music
- Lunch
- 0.0 Car Decal
- Fun at Tributary Brewery in Kittery, Maine!!!!

0.0

THIS OR THAT



CYCLE



0.0

NEW THIS YEAR

0.0 RUN

IF YOU LOVE EVERYTHING ABOUT ROAD RACING EXCEPT THE RUNNING PART, HAVE WE GOT THE RACE FOR YOU. THE SEACOAST SAFARI 0.0 RUN WILL TAKE PLACE JULY 15 IN CONJUNCTION WITH OUR CF CYCLE FOR LIFE. SEACOAST SAFARI 0.0 RUN WAS STARTED TO BRING RUNNERS AND NON-RUNNERS ALIKE TO ENJOY THE BEST PART OF ANY RUNNING EVENT—THE POST-RACE FESTIVITIES. AND YES, THIS IS REAL. NO EXCUSES, NO LIMITATIONS, ANYONE CAN DO IT.

Participants will receive bib numbers and will line up as if they were going to race, but the start will also be the finish. Participants will be able to proudly sport their event bibs without necessarily having to do all the training that goes along with traditional races. It's the perfect "race" for injured runners, too.

SWING FOR CF October 2

Mark your calendars for our annual fall golf event.
Golfers can now register for Swing for CF.

Register: events.cff.org/swingforcfnh

Calling CF Artists and Crafters!

The CF Foundation would love to
include unique auction items from our
CF Community to our Fall Auctions.

Please contact lgilbert@cff.org if you would
like to donate a craft or artwork.