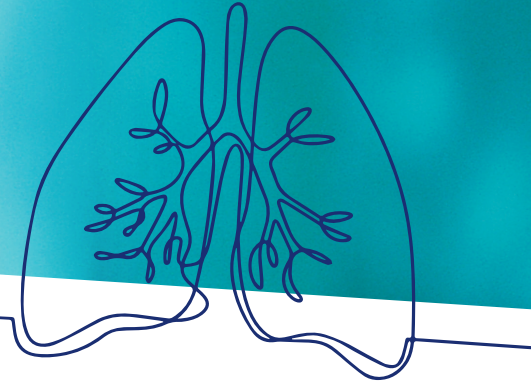


CYSTIC FIBROSIS

Patient & Family Advisory Council

DHMC CF Center



**Spring 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 K. Dutille, Roni I. Finkelstein, Paula Garvey, Kristin McCarthy, Ashlee Robinson and Sarah Vooris,



What's inside?

Walk-O-Rama!
CF Community News
Roni's Corner
and much more

Follow
Us



The “Let’s Get Moving edition!”

Spring is coming,
**LET’S GET
MOVING!!!**

Can you do 66,000 steps (or equivalent) per week, roughly 9,500 steps per day. We can help you! Register for our NH CF PFAC Walkorama! The Walkorama will be running from March 1st to April 30th! All you have to do is register, keep a record of your activity, log it each week and win prizes! So simple!

WALK-O-RAMA

What?

Get walking! Keep track of your daily steps and each Friday, register your steps.

Who?

DHMC CF Care Center patients, families and CF Team.

Why?

- Get fit in time for Spring
- Win prizes
- Have fun

When?

March and April

How?

Register using the QR code or this link bit.ly/nh_cf_walkorama Update your activity each week.

Questions?

nhcfpatientfam@gmail.com

Highlights

- A prize for every registered participant
- Weekly prize drawings for everyone who submits their steps
- Prizes for the top ten steppers

Stay connected

Email with questions
Follow us on social media
Check out our website
Send us your photos



nhcfpatientfam@gmail.com



www.nhcfpfac.com



New Hampshire Cystic Fibrosis
Family and Friends



[nh_cf_pfac](https://www.instagram.com/nh_cf_pfac)



Beam CF offers free fitness classes thanks to a grant from the CF Foundation. Follow the link >

How to track steps
with an Apple watch:
youtu.be/4NFYxwG6HqC

Why exercise?

Exercising With Cystic
Fibrosis (CF) | Everyday
CF (everyday-cf.com)

Step Conversion Chart

Use the chart below to determine the activities equivalent number of steps.

Simply multiply the **time** you did the activity by the **number of steps** indicated on the chart. For example, 30 minutes of canoeing equals 2,730 steps. (30 minutes x 91).

Activities	Steps/Minute*	Activities	Steps/Minute*
Aerobic dancing class	127	Dancing, party	109
Aerobic fitness class	181	Drill team	153
Aerobics, low impact	125	Electronic sports, Wii/PS3	91
Aerobics, step	153	Elliptical trainer, medium pace	203
Archery	102	Elliptical trainer, fast pace	250
Backpacking	181	Fencing	182
Badminton, casual	131	Firewood-carrying/chopping	60
Badminton, competitive	203	Fishing	91
Ballet dancing	120	Football	199
Baseball	130	Frisbee	91
Basketball, game	145	Gardening-weeding, (seated/kneeling)	80
Basketball, recreational	130	Gardening, hoeing, moderate	93
Bicycling, easy pace	130	Golf, carrying clubs	109
Bicycling, moderate pace	170	Golf, powered cart	80
Bicycling, vigorous pace	200	Grocery shopping	67
Billiards/pool	76	Gymnastics	121
Bowling	71	Handball, competitive	348
Bowling on the Wii	61	Handball, recreational	145
Boxing, non-competitive	131	Hiking	172
Boxing, competitive	222	Hiking, orienteering	232
Calisthenics	106	Hockey, field and ice	240
Canoeing	91	Home/auto repair	91
Cheerleading	100	Horseback riding	90
Children's playground game	136	Horseshoes	71
Circuit training	199	Housework, light	72
Cleaning the house	78	Housework, heavy	140
Climbing, rock/mountain	270	Ice skating, general	84
Cooking	61	Ice skating, moderate	122
Croquet	76	In-line skating	190
Dancing, class	109	Jogging	181
Dancing, salsa/country/swing	109		

*Steps/Minute equals steps per minute.
*Conversions are estimates. Your actual steps may vary

Step Conversion Chart cont.

Activities	Steps/Minute*	Activities	Steps/Minute*
Judo & Karate	236	Snowboarding	182
Jumping rope, fast	300	Snowmobiling	106
Jumping rope, moderate	250	Swimming, leisure	174
Kayaking	152	Snowshoeing	181
Kickball	212	Soccer, recreational	181
Kickboxing	290	Soccer, competitive	145
Lacrosse	242	Softball	152
Line Dancing	139	Spinning	200
Martial Arts	222	Squash	348
Miniature golf	91	Stair climbing, machine	200
Mopping	60	Stair climbing, down stairs	71
Mowing lawn	120	Stair climbing, up stairs	181
Painting (a room)	78	Stretching	15
Pilates	91	Surfing	91
Punching bag	180	Swimming, backstroke	181
Ping Pong	121	Swimming, butterfly	272
Raking lawn/leaves	121	Swimming, freestyle	181
Racquetball, casual	181	Swimming, treading water	116
Racquetball, competitive	254	Table tennis	120
Rock climbing	244	Tae Bo	250
Rollerblading	156	Tae Kwon Do	290
Rowing	147	Tai Chi	40
Rowing machine	212	Tennis	200
Rugby	303	Trampoline	90
Running, 12 - minute mile	178	Vacuuming	94
Running, 10 - minute mile	222	Volleyball	91
Running, 8 - minute mile	278	Walking, stroll	61
Sailing, boat and board	91	Walking, average	84
Scrubbing floors	71	Washing a car	71
Scuba Diving	203	Water aerobics	116
Shopping	70	Water polo	303
Shoveling snow	145	Water skiing	145
Skateboarding	102	Waxing a car	80
Skee-ball	52	Weight lifting	90
Skiing, light/moderate	109	Wrestling	145
Skiing, cross-country	114	Yard work	98
Sledding	158	Yoga	45

Healthy Eating

When trying to get fit for the summer, eating healthy food is important—check out these simple healthy recipes!

foodnetwork.com/healthyeats/recipes/2015/07/10-quick-and-easy-fitness-foods

If you would like some great recipe ideas for healthy eating when training check out *Run Fast, Eat Slow* and *Rise and Run* by Shalane Flanagan and Elyse Kopecky, available to borrow at your local library.

runfasteatslow.com/

What's Next?



In May

Register for the for your local CFF Great Strides taking place in May.



In June

Join the race for a cure at the 15th annual Bow Lake Dam 15K/5K Race to Cure cystic fibrosis, June 3rd in Strafford, NH!

With two scenic courses for both runners and walkers, the annual Toddler Dash, and a post race celebration at the lake—this is the family friendly event that you won't want to miss!

Register to participate or volunteer:
bowlakedam15k5k.com

WALK-O-RAMA

Meet our amazing Ambassadors:
Kerri, Heidi and Josh!

Kerri is currently training for the Boston Marathon.

"I started running in 2012 as a new challenge for myself after participating in a clinical trial which turned out to be one of the best decisions that I've made. It started out as something to do for more physical activity, but it grew into something that I love. Running has not only allowed me to see new places and experience things that I never thought I would, but I believe it is helped me stay as health as possible even during tough times. Another unexpected benefit is how it's helped me manage stress by being outdoors, breathing fresh air, and finding joy through movement.

Please join us for the inaugural Walkarama Challenge. All types of movement are included—not just walking and running—you may choose any activity including yoga, hiking, or even cycling. This can be done individually or with a team. You may just find an activity that you love and hopefully will continue to enjoy long after the challenge ends."



Heidi enjoys being active and being outside!

"Being active has always been a big part of my life. And has certainly helped manage my CF through the highs and lows. Trikafta has allowed me to get to doing the many things I love—particularly being outside, hiking, horseback riding and skiing. Walks with my dog are the highlight of each day. Getting outside and exploring is our favorite thing to do!"

Fifteen year old Josh's love of cross country running keeps him fit

"I keep fit by doing anything physical that I enjoy doing, mostly running cross-country and track. I love running because it gets rid of the stress in my life. It's freedom because I don't have to think about or stress about anything happening around me."



Roni's Corner

Compass Resources and Medicaid Redetermination

Many of our patients and families use CFF Compass resources to navigate the complex world of insurance coverage. Compass is a personalized, one-on-one service that provides people living with cystic fibrosis and their families a partner in dealing with challenges related to life with CF, no matter where you are in your CF journey. AIRS-accredited Compass case managers help with complex challenges, including understanding insurance basics, troubleshooting insurance coverage issues, seeking financial assistance for medical care and other living expenses, finding answers to legal questions related to work, school, disability/government benefits, and much more.

Recently, Aaron Stocks, who is an operations manager at Compass, reached out to me to discuss Medicaid redetermination and how Compass can be most helpful to our community. He graciously offered to be cc'd on emails that our patients send to Compass in order to make these requests feel more personal. From now on, when you send a service request to compass@cff.org, you can cc Aaron at astocks@cff.org for more personalized service.

The Compass team also helped us dig into the upcoming Medicaid redeterminations as the COVID-19 federal public health emergency ends. Here is the state-specific information they sent us. Please reach out to me via myDH or by phone if you have questions about how to access these resources; 603-650-5202.

New Hampshire

Deadline for re-determination is March 31st.

There were yellow letters that went out informing individuals of that as well.

They do have a COVID-19 list and that's where these letters are generated from.

If anyone has not completed their re-certification or home information, their cases will close as of March 31st, which means their Medicaid coverage will be no longer valid.

This is when they can explore other insurance option through the federal marketplace

If someone is deemed still eligible, NH Medicaid has 10-15 days to reprocess from when the redetermination date is received.

ie: If they provide their re-determination information by March 21st and they can't get to you by April 2nd, it will be acceptable as long as nothing else is needed.

If someone is still eligible and calls after the 31st; individuals will have to re-apply through their NH Easy account, call in, or go into the local office.

Vermont

Notices are going out in February to individuals whose Medicaid plans are ending in April either phone calls, text, and letter and then another reminder in May.

If an individual does not respond by the end of the reminder month, their plan will be terminated.

Each month has a different "wave" of notices for a 12 month unwinding period (ie: March notices are for plans ending in May with a reminder in June, etc.)

These notices are determined based on the end date of their eligibility.

Everyone has different end dates that is stated in that notice that is going out.

Individuals are supposed to call in or go in their portal and update anything that may need to be made.

When they call or go online, they can do the update immediately; there is no processing turnaround time.

Advocacy Update

February 2023

By Sarah Vooris

Ensuring patients with cystic fibrosis have access to affordable, high quality, specialized care is a key mission of the CF Foundation. To help fulfill this mission, advocacy aimed at helping state and federal decision makers understand what it's like to live with the complex disease of CF is needed. Advocating allows us to represent ourselves and speak on behalf of others. By telling our stories, our government representatives learn more about our experiences with CF and grasp more of what is going on in the larger CF community.

Two focuses of the CFF's advocacy work this year are addressing antimicrobial resistance (AMR) and the development of antibiotics and lowering out-of-pocket costs by banning accumulator programs utilized by insurance companies. Whether you currently have direct experience with these issues or not, please consider adding your voice to advocate on behalf of all those in the CF community.



Advocate

Help raise awareness and inspire action for people with CF

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.

To learn more about the 2023 advocacy priorities of the CFF, check out the following resources:

Antimicrobial Resistance and new Antibiotics

bit.ly/3KU0dmE

cff.org/media/28491/download?inline

XoC Survey Update

By Sarah Vooris

XoC Team - Patient/Family Representative

The XoC survey is a post-visit survey that is short and easy to take. It asks about in-person and virtual care experiences. Kept anonymous, the survey is not linked to patient names or birthdates. The XoC survey is designed to have a big impact without being another burden—no long phone calls or dozens of questions.

Based on feedback from XoC survey teams across the country, patients and families will be sent the survey once every three months following a visit with the CF care team either in-person, telehealth, or both in-person and telehealth in 2023. There will be no reminders. Patients and families may choose to take the survey as many times as they choose.

You can expect the survey link to come via text message the week following your clinic visit. The survey system uses the phone number you supplied to the team. It's important that the CF team has your correct and preferred phone number and email address on file. If the survey isn't completed via text, those with an email address on file will receive an email with the survey link.

With the new year, there are also changes to the questions on the XoC survey. The CF Foundation's XoC team leaders partnered with centers to improve the process and implementation of the survey. Changes to the data and narrative questions in the survey this year are a result of that work. The new questions and potential of quality improvement that may stem from them is exciting.

▶▶▶ **The XoC survey continues to be a key piece in adding the perspective of patients and families to make change and support practices that work for us. The more surveys taken, the more obvious the patterns become of what's working well and what needs improvement. Share your perspective and help improve care for everyone with CF.**

What you have to say matters.

CF Foundation Northern New England

Check out their latest newsletter for upcoming events, news and more! >



CF Community & CF Center News

Research opportunities

Scientific advances are happening quickly in the CF community and we know that you want to be a part of the discoveries even when those research trial are not being offered at DH. Your DH research team (to include your CF caregiver) has knowledge of studies occurring elsewhere that you may qualify for that we would love to share with you and the expertise to make seamless referrals to those centers (near and far) if you are interested in learning more about a specific trial(s). Check out ongoing trials at apps.cff.org/trials/finder, and connect with your CF Team for more detailed information. There are lots of great opportunities!



Congrats to Nathan, living his dream of being a firefighter



Awards Season!
Our very own Hannah on stage playing Maurice in *Beauty And The Beast*



MJ, age 11 with CF, first nordic (cross country) ski race!



March is National Nutrition month!

As we await revised nutrition guidelines for the CF population it is advised to follow a diet rich in fruits, vegetables and whole grains, while cutting down on animal fats, processed foods, and sugar. Stay tuned for news on updated recommendations and check out MyPlate | U.S. Department of Agriculture for great healthy recipes and ideas!

National Nutrition Month

H	O	P	T	U	O	C	M	P	S	F	S	L	P
G	C	A	L	O	I	H	R	H	P	L	U	A	C
S	U	G	A	R	P	O	S	C	I	U	R	B	S
H	E	U	C	N	E	L	D	H	C	I	O	E	P
A	E	I	A	I	G	E	A	I	E	D	H	L	O
P	C	S	O	M	G	S	S	C	S	S	P	P	T
N	P	A	N	U	S	T	H	K	M	O	S	P	A
S	H	A	C	B	O	E	H	E	U	S	O	A	S
L	A	U	E	L	O	R	H	N	I	R	H	L	S
U	S	S	I	A	P	O	P	H	C	A	P	I	I
E	A	O	E	D	L	L	P	A	L	S	R	C	U
S	L	L	I	R	O	L	R	S	A	S	O	P	M
F	I	S	H	H	U	S	S	U	C	C	S	H	A
C	F	F	O	O	D	L	A	B	E	L	D	M	U

POTASSIUM
CALCIUM
CHOLESTEROL
APPLE
CHICKEN
SUGAR
EGGS
FLUIDS
SODIUM
ALBUMIN
FISH
FOOD LABEL
HOT DASH
PHOSPHORUS
SPICES

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