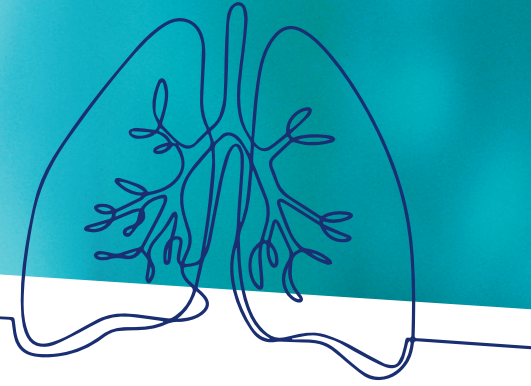


CYSTIC FIBROSIS

Patient & Family Advisory Council

DHMC CF Center



Holiday Issue 2022

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, Jennifer Stover and Sarah Vooris,

What's inside?

CF Community News
Updates from NACFC
CF Family Night Recap
Roni's Corner
and much more



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Us



CF Community & CF Center News



Henry was delighted when his mom brought him home a raffle prize from Patient and Family Education Night.



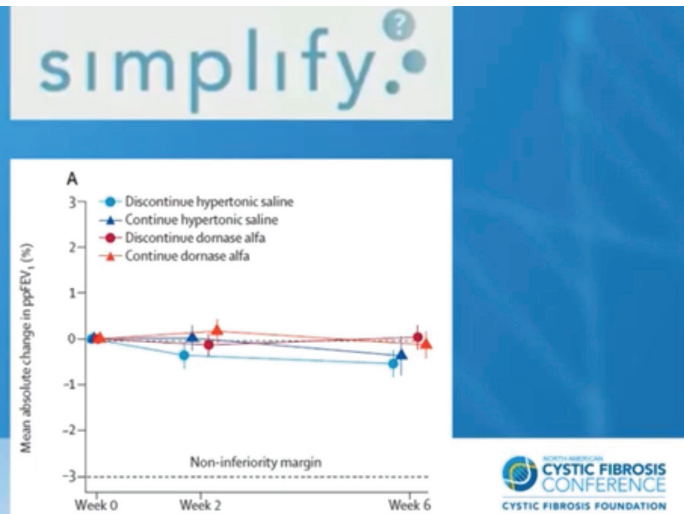
PFAC Member and CFF fundraiser support our CF Center

"Taste for a Cure is one of my favorite events and I was so excited to see that this year a basket of grocery cards was added to the auction items. Discussing project ideas at a PFAC meeting, team members shared how they navigate pulling together resources to help patients and families with the rising cost of gas, food, and other living expenses in addition to their CF care expenses. When I saw this item at the auction, it was a win, win—help the team and help other families." *Kathy*



Jess says Aloha from Hawaii!

Kerri dressed for the season when running the Santa Shuffle 5k—well done Kerri!



Congratulations and THANK YOU to the 31 patients in our Care Center who participated in the SIMPLIFY Study! The results were shared at NACFC. Talk to your team to hear the exciting findings. Participation in research students benefits all of us. To learn more about research study participation, talk to your team.

North American CF Conference

The North American Cystic Fibrosis Conference was held in-person from Nov 3-5, 2022 at the Pennsylvania Convention Center in Philadelphia, PA. We were very excited to be back in person again and fortunate to have many representatives from our Dartmouth Health CF Care Center attend. Members of the CF team learned about the latest research findings and also presented research findings from their own investigations. It was such a lively time in Philly with the local team playing in the World Series. We worked hard, but still found time to explore the city and network with other CF Centers. There were so many brilliant people there, sharing research and experiences.



We all took something different home—here are a few insights that our team would like to share!

Best success stories in recent medical history – Aids, Hepatitis C and **Cystic Fibrosis!**

53 is predicted life expectancy this year, that is the biggest increase in a year, EVER!

Research using mRNA opens door to other diseases, and this seems to be our best hope.

Gene therapy that will help other diseases

CF is one of the best stories in medical history, over 7,000 people participating in research trials

So much research- mRNA, lung transplant (not just CF) everyone is thought of.

7% of the population do not have treatment options like modulators.

Even with modulators CF is a really complicated condition to live with. Mental health issues are hugely impacting the community.

A person w/cf is 3 times more likely to experience food insecurity.

As the population ages, new challenges are arising – mental health, transplant, colon cancer, obesity.

Continued advocacy is essential to ensure access to drugs and do much more.

NACFC 2022—All recordings now available!

This year's NACFC is now available on demand! The recordings, including the plenaries, symposia, many discipline groups, and lunch & learns are available on YouTube so you can watch whenever and wherever you want to.



“The SIMPLIFY study shows that for people with good lung function who are taking ETI (Trikafta), stopping Pulmozyme is safe and may even be beneficial.” *Dr. O’Sullivan*

.....

“CF teams are supported by a strong multidisciplinary community with a huge focus on continually improving care for people living with CF. We all do our best work when we can learn and develop improved models of care together.” *Dr. West*

.....

“I want to relay the importance of exercise; in a study of those who exercised (strength and aerobic) for 3 hours per week after 3 months had a 15% increase in lung function.” *Kate LaMare*

.....

“It was great to see so many brilliant and passionate people in one place on the same mission. My big takeaway is that even though there has been huge progress in the treatment of CF, there is still no cure and the CF community will not rest until there is a cure.” *Paula Garvey*

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“I’m excited to see life expectancy rise, along with the number of adult subjects, compared to the pedi population.” *Barbara Rodgers*

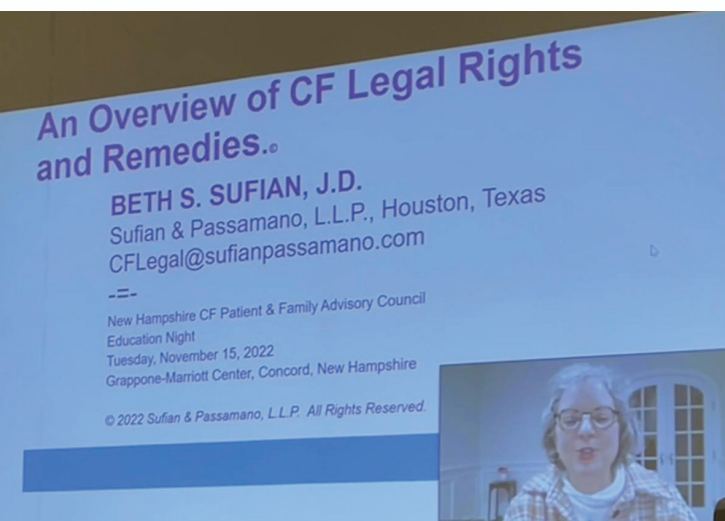


NH CF Patient and Family Education Night

In early November over 70 people with a CF connection attended our CF Education Night in person at the Graponne Center in Concord, and virtually. We were delighted to have the opportunity to get together again and catch up with the latest news and updates from NACFC and more. We had an opportunity to meet with representatives from pharmaceutical companies, Make-A-Wish Foundation and The Cystic Fibrosis Foundation Northern New England Chapter. View the video.

- To start off the evening we were introduced to new CF team members. It was great to welcome all our new members.
- Lisa O'Connor, Executive Director CFF NNE, shared the great work being done by the CFF and thanked us for being part of the CFF. Grampions, CF Fighters and CFF Cares events provide a space to discuss and navigate our CF journey. Advocacy is very important with the PASTEUR Act being a recent focus.
- Dr. Julia West then shared information from the North American CF Conference, including mRNA technology, and other therapies. Please check the Family Night recording for more information. Dr West's final slide ended with "The future is very bright!"
- Our NH CF center is participating in research studies. Dr. Dan Ardigides shared information on local research updates from our Center. He highlighted the SIMPLIFY study that our center participated in recently. There are also ongoing studies on the gut microbiome, interactions between different bacteria, the impacts of aspergillus on the CF lung, and more. If you would like to hear more about participating in these studies, please contact Dana Dorman at dana.b.dorman@hitchcock.org.





- Next, Dr. Brian O’Sullivan shared the latest information from the CF registry and our CF center. This information is gathered at the clinic and provides us with national trends. This gives us an idea on how our center is doing and how we can improve. Quote of the night from Dr. O’Sullivan was “You guys are going to put us out of business with the successes that have been made in the past few years.” The big takeaway is that our program has some of the best lung function and weights in the country!

- The importance of the Experience of Care Survey was shared by our social worker Roni.

- Paula Garvey gave a Patient and Family Advisory Council (PFAC) update and shared information on projects we have completed this year.

- Compass is an important resource of CF patients and Families. Kelly Muldowney shared details on how we can connect with Compass, what they do, and how they support patients and families. Compass is a team of CF patient advocates that provide assistance with insurance coverage, financial assistance, legal questions, and much more. This is a free service. Email compass@cff.org for details.

- We were delighted to welcome our guest speaker Beth Sufian J.D., director of the CF Legal Information Hotline. Beth gave us a very detailed presentation on her work. Please watch the recording for the details she shared. To contact Beth, call 1-800-622-0385 or email CFLegal@sufianpassamano.com.

- And lastly, we were delighted to welcome our keynote speaker, Gunnar Esiason, in person. Gunnar shared information about the Boomer Esiason Foundation, his CF journey and his fertility journey. His presentation is worth watching. Please also check out the Boomer Esiason Foundation website - <https://www.esiason.org/>

Overall it was an amazing night. Thank you to everyone who participated. If you have any suggestions or ideas please let us know. We are looking forward to our 2023 event.

Nutrition in the age of modulators

Updated nutrition information in the era of modulators is being currently revised. It has been noted that the CF dietary recommendations may need to change. Until the new recommendations are released the advice being shared is to follow the Mediterranean Diet.

The great thing about following this dietary plan is that it reduces the risk of heart disease and stroke, so the whole family benefits. 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. And bonus, these tasty meals are so colorful and pretty. Here are a few recipes based on the Mediterranean diet for you to try.

20 Popular Mediterranean Diet Dinners

Blackberry Cobbler



nutrition
modulators

Holiday Coping Tips

Welcome to the holiday season! I won't get too detailed about the stressors that come up for folks during this time—they're too numerous to count. Instead, I'll list some ideas for how to cope during this time.

- 1. Consider a technology detox** – whether or not you spend the holiday with family, looking at social media portrayals of the season may bring up feelings of envy, self-doubt, and anger. Giving yourself a couple days off from technology may help you stay more present in your current circumstance.
- 2. Find ways to stay active** – staying active looks different in every body! Take a moment to define for yourself what it looks like for your body to stay active. Exercise is an adaptive way to relieve stress and maintain your mental health.
- 3. Make plans in advance** – this tip applies to folks who may live alone or who don't have larger families to spend the holidays with. Think about who you might enjoy spending significant days with and call them! Make a plan to spend time together in person or online. Knowing that you have something on your calendar may ease stress around spending holidays alone.
- 4. Reflect on the past year** – many of us tend to look ahead toward the next year, but sometimes looking back allows us to explore ourselves more fully. Consider using the month of December to reflect on this past year—here are some ideas for reflection questions:
 - What's a significant experience that has affected you over the past year? How did it affect you?
 - Think about a major milestone that happened with your family this past year. How has this affected you?
 - Is there something that you wish you had done differently this past year? Or that you're especially proud of?
 - Describe an event in the world that has impacted you this year.

I hope you all enjoy the holiday season. As always, you can reach out to me over MyDH or by phone if you have questions, comments, or concerns about anything related to mental health or resources. If you'd like to talk to someone about how you're feeling during this holiday season, here are some resources:

- In **non-emergency situations**, contact the NAMI Helpline. They are available Monday–Friday from 10 am until 10 pm. This line is staffed by peer specialists who can offer support and concrete next steps.
- If you are experiencing a **mental health crisis** call 988 or your local mobile crisis line. You can easily find your local number by googling your city, state, and "mobile crisis".
- If you are experiencing an **emergency**, like feeling actively suicidal, call 911 or go to your local emergency department. Notify the operator that it is a psychiatric emergency and ask for police officers trained in crisis intervention or trained to assist people experiencing a psychiatric emergency.

XoC Survey

The Experience of Care, or XoC, is a new survey designed to help CF Centers and the CFF understand care as it's experienced by people with CF and their families. Our voices are key as our center aims to provide the best quality, patient-centered care possible.

Check out this short video that explores the XoC—what it is, how it works, and why it matters.



CF Scholarships and Financial Aid

Many scholarships and financial aid options are available for students with cystic fibrosis who want to pursue higher education. Numerous types of scholarships are available based on different criteria. Scholarships based on being involved in athletics, having a specific skill or ability, having cystic fibrosis, or having a chronic disease in general are examples of such criteria. When starting your search, it is helpful to consider the types of scholarships for which you may be eligible.

Below are a few sites to help you get started as you investigate scholarships:

NeedyMeds maintains a list of CF-specific scholarships

<https://bit.ly/3G0U6ZJ>

The Federal Student Aid Information Center at the U.S. Department of Education provides information about finding grants and scholarships, including tips on where to look for them.

<https://bit.ly/3Vcu5fs>

The National Association of Student Financial Aid Administrators has a database of financial aid options that you can search for by state.

<https://bit.ly/3FFOLbx>

If you would like additional help finding scholarships, call Cystic Fibrosis Foundation Compass at 844-COMPASS (844-266-7277) Monday–Friday, 9 am until 7 pm ET, or email compass@cff.org.



CYSTIC FIBROSIS FOUNDATION

Registration is Open for Our 2023 Ski for the Cure!

We are so excited to be back in person for our 30th Anniversary Ski for the Cure!

March 17-19, 2023

Omni Mount Washington
Resort and Bretton Woods.

**REGISTER
TODAY**

BREATHECON | CYSTIC FIBROSIS FOUNDATION®

The Cystic Fibrosis Foundation will host BreatheCon, a free, two-day virtual event designed by and for adults with cystic fibrosis which provides the opportunity to connect, share, and learn from others with CF through open and honest dialogue.

February 24 & 25
2023

SIGN UP

to receive email updates and be notified when registration opens and the agenda is posted.

CF Foundation Advocacy

Be a Voice for Cystic Fibrosis

Get Involved.

Speak Out.

Inspire Action.

The decisions of elected officials can impact the ability of people with CF to go to their care centers and access therapies, and also can affect vital CF research. Your voice is critical to ensuring that those officials join us in adding tomorrows to the lives of those with CF.

Become an advocate to:

- Promote access to care
- Advance CF research and development
- Raise awareness of CF

National Advocacy Co-Chairs



Chad Riedy, Jaci, and Drew Strube



TEXT 'FIGHTCF' TO 52886

cff.org/advocate

Introducing... Beam Cystic Fibrosis

Online exercise,
education, and
wellbeing support
for people living
with cystic
fibrosis



Beam CF has
been created just
for you, offering
progressive programs,
live and on-demand
classes and community
support



Scan the code or head to
beamfeelgood.com to sign up.



Thanks to the Cystic Fibrosis Foundation, adults (18+) with cystic fibrosis in the United States have free access to Beam until the end of the year.

Helping children with cystic fibrosis to find movement they enjoy



We believe that healthy habits are best planted young

Physical activity is really important to help manage life with cystic fibrosis - physically, mentally and emotionally.

We help children with CF and their families to find movement that they enjoy so they are more likely to stick at it as they grow into a teen and a healthy adult.

We have on-demand and live sessions including:

- Mini sessions for CF clinic appointments
- Stretches to help with your lung function tests
- Airway clearance support + Vest sessions
- Calming practices
- Play-based exercise
- Breathing exercises
- Education
- A mix of cardio, strength and flexibility classes

A collaboration between Johns Hopkins CF Center, Beam and CF Yogi

Sign up for free at beamfeelgood.com/cf-youth



beam
movement to feel good

CFYOGI
yoga for cystic fibrosis

seasons /
greetings
and happy
new year

