

# SUMMER NEWSLETTER

**DHMC  
CYSTIC FIBROSIS  
PATIENT AND FAMILY  
ADVISORY COUNCIL**

## WELCOME TO OUR CF PFAC SUMMER NEWSLETTER!

Happy summer! We are very excited to be bringing you our DHMC CF Patient and Family Advisory Council summer newsletter. The information is very relevant to summer life so we hope you find time to read it. We are delighted to share information from our amazing Pharmacy team about Trikafta, Spotlight on research nurse, Dana, and lots more!

Please email us at [nhcfpatientfam@gmail.com](mailto:nhcfpatientfam@gmail.com) if you have suggestions or questions, or are interested in being part of this group. We are 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.

### 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 patients and families for the highest quality of care.

## FOLLOW US ON SOCIAL MEDIA



**NEW HAMPSHIRE CYSTIC  
FIBROSIS FAMILY AND FRIENDS**



**@NH\_CF\_PFAC**



**@NH\_CF\_PFAC**

## What's inside this issue:

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NORTHERN NEW ENGLAND CHAPTER**



# NEWS FROM OUR DHMC

## CF CARE CENTER

### TRIKAFTA:

## NOW AVAILABLE FOR YOUNGER CHILDREN!

Brian Bourque, PharmD, CSP and Emily Dutille, PharmD, CSP

The FDA recently expanded approval of Trikafta to include children ages 6 through 11 with certain mutations. Here are some common questions that our team receives.

#### How does Trikafta work?

For people with cystic fibrosis, the body is either unable to make a particular protein, get that protein to the right area, or tell that protein to work correctly. Trikafta contains three ingredients that all work together to improve that process at different stages. Individual responses may vary, but this medication has been shown to improve pulmonary function tests, help with weight gain, and improve other cystic fibrosis symptoms, not limited to its effects on the lungs.

#### How should I take Trikafta?

It is important to take Trikafta and all of the other modulators (Kalydeco, Orkambi, and Symdeko) with food that contains some fat, such as peanut butter, avocado, ice cream, or whole milk to help the body absorb the medications. It is also important to avoid grapefruit juice and certain medications. This is why your pharmacists and providers always ask if there are any medication changes we should know about.

#### What side effects can happen with Trikafta?

Trikafta is usually well-tolerated. The most common side effects are headache, upper respiratory tract infections, stomach issues, rash, influenza, or changes to liver function tests. Most of these side effects are mild and your clinic team has good strategies to deal with them. Please reach out to us if you have any of these and want some suggestions on how to fix them. We check liver function tests every 3 months for the first year and annually after that, sometimes more frequently. For anyone under 18 on one of these medications, we need to have an eye exam completed each year.

#### How do I get started on Trikafta?

Our clinic and pharmacy team was bracing for this approval. If your child is eligible, you have likely been contacted for what to do. We will check to make sure we have an up to date eye exam, liver tests, and that the medication is appropriate. Once that is all set, we explain to the insurance company why they should cover the medication. If you ever have any difficulty filling (or refilling!) your medications, don't hesitate to reach out to your clinic pharmacist!

# SPOTLIGHT ON DANA DORMAN

## RESEARCH NURSE

INTERVIEW BY SARAH VOORIS



Soon after my daughter's diagnosis with cystic fibrosis in 2008, I connected with another mom of children with CF who encouraged me to check out the drug development pipeline on the CF Foundation's website. Undoing my confusion, she shared that "the pipeline" was in fact a list on the Foundation's website of potential medicines for CF that were under investigation or which had already been approved for use. "Have hope," she encouraged, "There are medicines being researched to address lung issues and GI symptoms - even to correct the underlying cause of CF. Some are in phase one of trials."

Little did I know that my daughter would quickly become part of research related to CF. It started with sharing BM samples and included participation in a trial for the modulator (corrector) medicine that was in phase one of trials when she was a newborn. As I became more involved with the CF community, building understanding of the disease and caring for my daughter and her needs in the present, I quickly realized we were not alone. There were people both past and present working tirelessly on behalf of individuals with CF, some of whom were involved with research aimed at treating and ultimately curing the disease.

One such individual is Dana Dorman, a CF research nurse at DHMC. Our family connected with Dana through our involvement with CF research studies. We added to our knowledge of her and the work of CF research programs through a recent interview for this newsletter. Check it out below to learn more about one person and her experience working relentlessly on behalf of those in the CF community. Thank you, Dana!

Why did you become a nurse? What is your favorite thing about being a nurse?  
I LOVE ANIMALS! As a young child I wanted to be a dolphin trainer but my aversion to the smell of fish put the kibosh on that career so I set my sights on being a veterinarian. Lo and behold, I cried whenever I encountered an injured animal while volunteering at an animal hospital. Thus I turned to nursing. I wanted a job in which I could make a difference, connect with people, experience educational growth and work in a variety of settings with a variety of clientele in multiple specialties. In 40 years I have achieved three out of those four. Why? I fell in love with one of my first nursing school assignments - Little Summer A who had CF and I have stayed in love with my job in CF nursing ever since!

How did you get involved with doing research for CF?

My mentor in graduate school at the University of Washington was Dr. Bonney Ramsey, the architect of the clinical trial network known as the TDN, (CFF Therapeutics Development Network). Her passion for the advancement of care in CF was INFECTIOUS and I caught the research bug. For over two decades I have been directly involved in the TDN which has conducted more than 150 therapeutic clinical trials assisting in the development of novel treatments for persons with CF.

# SPOTLIGHT ON DANA CONTINUED

How are research studies chosen - the topics to study, but also the places where the studies happen? How do research studies usually work?

The CF registry collects data on everyone - when seen or hospitalized. This shows where the needs are. Right now we are focusing on a cure and modulators. We are also focusing on anti-infectives - like TOBI and Cayston. Another study, called the MAYFLOWER study, is focused on the reproductive health of women with CF.

To add to this question's answer, I really want to plug the book, *Breath from Salt* written by Bijal Trivedi. She beautifully captures the emotions of the families, the CF medical team and the scientists involved in clinical trials and their JOY as new drugs are approved. Put it on your summer reading list now!

Describe one of your most memorable research studies.

My most memorable study was the pulmozyme study as it was the first drug developed specifically for CF that resulted in FDA approval in 1993. It wasn't until 1997, that I had the satisfaction of working on another clinical trial that resulted in FDA approval. That study was for TOBI. I suppose you could say my career as a research nurse has mirrored the New England Patriots win/loss record. For years, we both worked HARD but fell short of the win. But how lovely it is to be the GOAT on a Cinderella Team now. Hypersal, Cayston, Kalydeco, Orkambi, Symdeko and now Trikafta and the pipeline of potential therapies that target CF from every angle is robust. CF, once a death sentence, has become a manageable condition...until sometime in the near future CF stands for CURE FOUND!

## Lightning Round

Eggs or pancakes? Eggs, unless it's pancakes for dinner.

Pumpkin pie or apple pie? Apple pie

Matching or mismatched socks? Matched

Fishing or kayaking? Kayaking. I love being active outdoors with family and friends, albeit, hiking, biking, swimming, kayaking, rock climbing, sailing...you get the picture.

Arctic or tropical? Tropical, but I've never been to the arctic.

Moose or hedgehog? Moose

Zoo or aquarium? Zoo

Puppies or babies? Puppies

How do you like your marshmallows cooked? Evenly browned. It can have a little bit of char, but I like the perfect s'more.



# Why we got our Covid-19 Vaccine

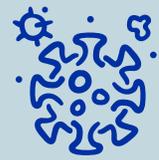
We asked our families and friends why they thought it was important to get vaccinated



## My Why

**V**iral invasion  
Tired of the **A**ltered life I've had for months  
**C**aring for others  
Who simply **C**an't  
**R**eturning to things loved and missed  
**O**ne shot makes  
**C**hange for all

- R. Vooris, age 12 with CF



"As an emergency medicine physician assistant I was exposed to COVID-19 every time I worked and was therefore among the first to be offered the COVID-19 vaccine. Like many others I had concerns about the safety of a vaccine that was developed and approved so quickly. As I took care of more patients with COVID-19 it became obvious that the risk of getting the disease was far worse than the risk from the immunization. In the end the decision was easy. It was my responsibility to protect my family, co-workers, patients and the greater community. So on December 16th I rolled up my sleeve and received my COVID-19 immunization."

Mike, CF Dad



"I got my vaccine to protect myself, my loved ones, my patients and my community. COVID-19 is a devastating virus and while LESS severe in children it can still cause symptoms short AND long term and death. Both NH and VT have several WALK-IN vaccine sites now. Just go to this simple CDC webpage to find a site and a specific vaccine near you.

<https://www.vaccines.gov/search/>. If you have any

questions or concerns please reach out to your primary care provider or your CF center team. We are here for you.

And your vaccine is waiting for you!"

Lynn, CF Nurse





# Why we got our Covid-19 Vaccine



"I got my COVID-19 vaccine not only to protect myself, but to protect those around me—such as post-transplant CFers, who are at a higher risk. I'm a public health student so I know how important it is to build collective immunity, even if you are not at a high risk yourself. I also did it so I could spend quality time with my friends without anxiety!"

Rosie, adult w/cf

"I got my Covid vaccine for my youngest daughter with cf. At the time she was too young to receive the shot. Our entire family, (sisters, brothers, grandparents aunts and uncles) all wanted to protect her. The best way we could do that was getting vaccinated. She has since received her shot too!"

Jennifer, parent of teen w/cf

"As someone living with CF, knowing I have that extra protection to keep me safe from COVID is comforting. It's very nice not wearing a mask and not being too worried about it."

Hannah, teen w/cf

"I chose to get vaccinated because I knew that it would keep myself and others safe. I couldn't have been more impressed and inspired by the ease of the process and the commitment of those working at the vaccine site. Now with the emergence of the Delta variant, I know I made the right decision."

Jack, adult w/cf

"I got my vaccine so I could hug my parents, grandparents, and nephews again! The vaccine gives me hope to see maskless kids playing together again and a break in the social isolation, constant anxiety and fear of the past 1.5 years for adults."

Torie, Child Life Specialist

"I got a COVID vaccine because I wanted to protect my son with CF, our family, and especially our grandparents. We've always done all that we could to keep my son healthy, getting a vaccine to keep him and us from getting COVID felt like the right thing to do."

Kathy, Mom of adult w/cf



## Good bye and Good luck!

**Good bye and thank-you to Dr. Gifford , Dr. Guill and Karin Hummel. We will miss you and wish you the very best of luck in your next adventure!**

For the latest Covid 19 News check out

<https://www.cff.org/Life-With-CF/Daily-Life/Germs-and-Staying-Healthy/CF-and-Coronavirus/COVID-19-Community-Questions-and-Answers/>



# **CF SUMMER LIVING**

## **DEHYDRATION AND HEAT-RELATED ILLNESS**

**CHILDREN AND TEENS WITH CF ARE ENCOURAGED TO PARTICIPATE IN ACTIVITIES, EXERCISE AND SPORTS ALL YEAR ROUND. HOWEVER, ANYONE WITH CF HAS AN INCREASED RISK FOR SALT DEPLETION AND/OR DEHYDRATION. PREVENTING THESE PROBLEMS REQUIRES ADULT SUPERVISION. CHILDREN AND TEENS ARE NOT ABLE TO SENSE THEIR INCREASED NEEDS FOR SALT AND FLUIDS IN STRENUOUS CONDITIONS. THEY NEED COACHING DURING ACTIVITIES FROM PARENTS OR AN ADULT WHO HAS RECEIVED TRAINING ABOUT THE SPECIAL NEEDS OF A CHILD WITH CF.**

### **PREVENTION OF SALT DEPLETION AND/OR HYDRATION PARENTS OR COACHES SHOULD:**

- BE AWARE OF THE CHILD/TEEN'S FITNESS AND TRAINING LEVEL COMPARED TO THE TYPE AND DURATION OF THE ACTIVITY**
- ASSESS ENVIRONMENTAL CONDITIONS (TEMPERATURE AND HUMIDITY)**
- MAKE SURE THE CHILD/TEEN IS ACCLIMATIZED TO THE CONDITIONS; SOMEONE UNACCUSTOMED TO STRENUOUS EXERCISE IN HEAT WILL BE AT HIGHER RISK FOR PROBLEMS. BEGIN SLOWLY AND ADVANCE GRADUALLY AS TOLERATED**
- MONITOR THE CHILD'S INTAKE OF SALT AND FLUID**
- ASK THE CHILD ABOUT URINE OUTPUT (SHOULD BE NORMAL AMOUNTS OF LIGHT COLORED URINE; SMALL AMOUNTS OF DARK OR STRONG URINE SUGGEST INADEQUATE FLUID INTAKE)**

**HEAT-RELATED ILLNESS BEGIN WITH SALT DEPLETION AND/OR DEHYDRATION. THESE PROBLEMS CAN HAPPEN QUICKLY, ESPECIALLY IN SMALL, YOUNG CHILDREN. PARENTS AND COACHES NEED TO BE ALERT, WATCHING FOR THE FOLLOWING PROBLEMS OR SYMPTOMS:**

- FATIGUE/EXHAUSTION**
- CONFUSION**
- WEAKNESS OR LOSS OF COORDINATION**
- FEVER (INCREASED BODY CORE TEMPERATURE)**
- PROFUSE SWEATING**
- MUSCLE CRAMPS**
- ABDOMINAL PAIN**
- VOMITING**

**Heat stroke, the most severe problem with salt depletion and/or dehydration, is associated with loss of consciousness, seizures, and kidney failure  
HEAT STROKE REQUIRES IMMEDIATE  
MEDICAL ATTENTION**



# CF SUMMER LIVING

## SALT AND CYSTIC FIBROSIS

### INCREASED NEED FOR SALT WITH CF

The right portions of sodium, chloride, and water in the body are essential for anyone, whether you have CF or not. CF causes a person to lose more salt (sodium chloride) in sweat, up to five times the normal. Because of the high salt losses with CF, levels of sodium and chloride in the body can drop. Inadequate salt intake over a long period of time may result in poor appetite and slow growth. Rapid depletion of salt and fluid can occur with illness or strenuous activity in hot weather.

Most of the time, people with CF regulate their salt and fluid levels by adding salt to their food, choosing salty foods, and drinking to match thirst. Infants and young children with CF need to be given small amounts of salt throughout the day.

## FLUID

Children and teens with CF greatly underestimate their fluid intake and may become dehydrated when exercising in heat. Parents and coaches need to encourage adequate fluids. Suggested fluid intake guidelines for activities or competitions that lasts longer than 30 minutes in the heat.

Time:	Fluid Amount:
1-2 hours before	10-14 ounces
10-15 minutes before	8-12 ounces
Every 30 minutes during	5-12 ounces (at least 1oz for every 20lb body weight)
After activity	16 ounces for every lb of weight lost during the activity

**\*Remember to adjust for individual needs, some individuals and some situations may require more fluid than the guidelines\***



# CF SUMMER LIVING

## TIPS FOR HEAT

### CF SPORTS DRINKS

Cold, uncarbonated beverages are recommended for use with activity in heat. Cold water is an excellent choice for children who are able to eat salty foods, such as pretzels, to get the salt they need. Frequent use of sweetened beverages or juices may cause dental decay.

For children and teens with CF who are participating in sporting events, eating salty food may not be possible. Standard sports drinks such as Gatorade or PowerAde do not provide enough salt for a person with CF. Additional salt needs to be added to sports drinks.

### SUGGESTER SALT SUPPLEMENTATION - INFANTS AND CHILDREN W/ CF

<u>AGE</u>	<u>RECOMMENDED SALT PER DAY UNDER USUAL CONDITIONS*</u>	<u>RECOMMENDED SALT PER DAY UNDER EXTREME CONDITIONS**</u>
0-6mos	1/8 - 1/4 tsp	1/4 - 1/2 tsp
6mos-1yr	1/4 - 1/2 tsp	1/2 - 3/4 tsp
1-5yrs	1/3 - 2/3 tsp	2/3 - 1 and 1/3 tsp
5yrs+	3/4 - 1 tsp	1 and 1/2 - 2 tsp

\*Usual conditions - Moderate temperature and humidity; no excessive sweating; regular bowel movements; no vomiting or diarrhea

\*\*Extreme conditions - High temperature and humidity; Dry, desert climate; strenuous and/or prolonged exercise (especially in heat); excessive sweating; fever, diarrhea, vomiting

Give salt in small portions throughout the day rather than one big dose. Salt tablets are not recommended for any child because they may cause nausea and vomiting. In addition, salt tablets don't trigger the same thirsty sensation as salty foods. Salt tablets can significantly increase the risk of dehydration.

These guidelines should be adapted according to individual need and the particular situation. Please contact the child's CF Center with any questions regarding these recommendations.

# A day at the beach



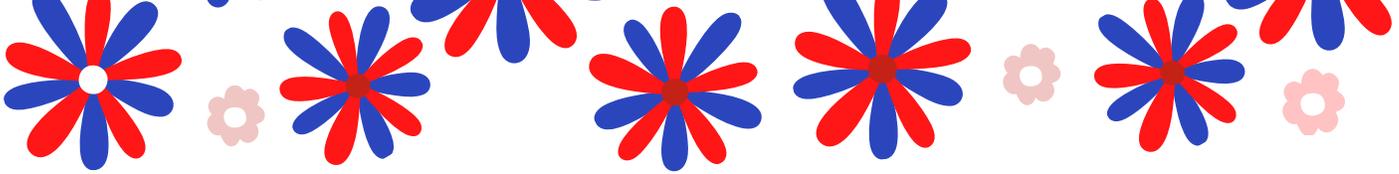
## Things to bring:

- Plenty of fluids
- Salty foods
- Extra enzymes
- Disinfecting hand wipes
- Sunscreen
- Umbrella for shade
- Cooler to refrigerate food and appropriate medications



## Helpful hints:

1. Physical activities are going to burn more calories. Pack trail mix with nuts, cheese and crackers, peanut butter and jelly sandwiches and chocolate milk. They are all high in calories and can help provide the necessary salt, vitamins, carbohydrates, and protein needed in your diet.
2. Exercising and being out in the summer will make you sweat. It is important to drink enough fluids and add in the extra salt to stay hydrated.
3. Slather on the sunscreen and reapply regularly. Certain antibiotics you are taking can make you sensitive to the sun. Read the labels if you're unsure. Bringing a beach umbrella will give you a place to escape.
4. If you're bringing medication that needs to stay cold, pack it in a cooler with ice. Remember to use disinfecting wipes to clean your hands before administering the medication if a bathroom isn't nearby.
5. Pack plenty of extra enzymes. Remember these do not belong in the cooler.
6. Have fun!! Build sandcastles, ride the waves and breathe in all that fresh salty air!



# CF 504 PLANS

Designing a 504 plan that works for your student with CF can be daunting, CF Mom and PFAC member Jennifer Stover would like to share this advice from her experience with designing 504 Plans.

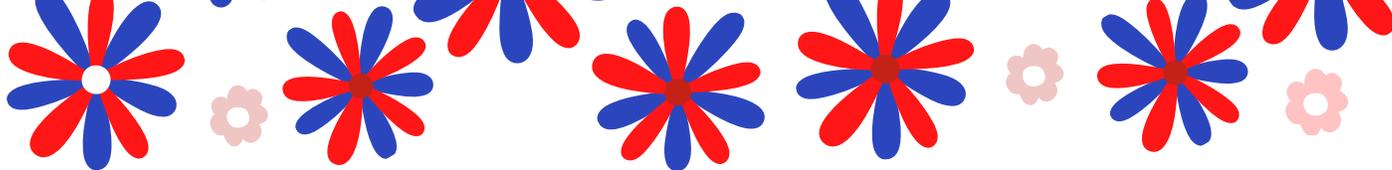
## Accommodations for K-5

- The student will take their enzymes under the supervision of the office staff, not in the nurse's office due to concern of other sick children being in there.
- Student will be allowed extra time to finish lunch or snack if needed.
- Student will be allowed to keep a water bottle at his/her desk and take it with them throughout the day.
- Student will be allowed to keep hand sanitizer at his/her desk and use it as needed.
- Student will have access to sanitizing wipes to clean his/her desk or work station as needed. (we always provided the wipes)
- Student will have access to the bathroom as often and as long as needed.
- If a fellow student is showing signs of illness (cough, sneezing, etc) the teacher will make sure CF student is far enough away.
- In the hot months of school, a portable air conditioner is installed in the child's classroom.
- Student will not be placed in a nut free classroom. (we did this because Abby ate a lot of snacks/lunch with peanut butter and nuts due to the fat content)
- A tutor will be provided in school or at home depending on the needs of the child. (one winter Abby was hospitalized twice and we didn't want to send her back until winter was over. The school provided a tutor to come to our house to keep her caught up on work)

## Accommodations for Grades 6-8

We kept all of the previous accommodations and added these new ones

- Student will not be placed in a classroom or on the same teaching team as another student with CF.
- Student will have access to the school nurse as needed. Teacher will notify the nurse that the student is coming down to make sure the other CF student is not already there.
- Student/Staff are aware the two CF students need to remain 6 feet away from each other.
- Student will take PE the second semester to assist with hot/humid weather concerns.
- Student will self-limit activity on hot/humid days as needed.
- School will work with student regarding any missing/make-up work and grading regarding extended absences if needed.



# CF 504 PLANS PART 2

## Accommodations for High School

At this point, Abby is responsible for own self care. Her 504 is written this way. Also, there was another student with CF in her school.

### THE STUDENT:

1. Will carry a 1 day supply of enzymes in his/her lunch bag and will be able to self-administer.
2. Will clean surfaces and hands as needed.
3. Will move his/her seat when concerned with other sick students.
4. Will access the school nurse as needed.
5. Will carry a water bottle as needed.
6. Will maintain a minimum of 6 feet away from any other child with CF.
7. Will work with teachers regarding any missing/make-up work and grading regarding extended absences if needed.

### THE PARENT:

1. Will continue with good home/school communication.
2. Will provide student with hand sanitizer/ and enzymes.
3. When calling student in tardy/absent/dismissal will notify the school when this is due to the medical condition.

## HELP IS AVAILABLE!

If you need advice on your 504 plan help is available at the Parent Information Center.

Contact Maureen Shields  
Parent Information Center  
54 Old Suncook Road  
Concord, NH 03301  
603.224.7005  
<https://picnh.org>

Or email the  
Cystic Fibrosis Patient and Family Advisory  
Council at [NHcfpatientfam@gmail.com](mailto:NHcfpatientfam@gmail.com)  
to connect with other families!



# Going to college with CF:

## Things to think about

### College Selection

- Do you want a big or small school?**  
While big schools may have more resources, small schools can make it easier to make a connection with professors and the various offices you may need
- Contact Student Accessibility Services**  
See what papers you need to submit from doctors, etc. to get accommodations
- Research their Health Services**  
It's good to make a connection in case you need something from them
- Do you have access to Counseling Services through the school?**  
Mental health is just as important as physical health!

### Housing

- Think about what would be best for you: a Single, Roommate or Suite**  
Medical singles can be a good option if offered
- Look into housing accommodations like:**
  - Air conditioning unit
  - Private bathroom
  - Lower floor to avoid stairs
  - Dining Hall Accommodations for dietary restrictions
- Think about how you will be able to clean your nebs**
- Sometimes living at home is your best option!**

### College Town

- Where is the nearest CF Center?**  
Will you commute to your home center or go to a local one
- Where is the nearest pharmacy?**  
It's often easier to transfer prescriptions from one branch of a pharmacy to another
- How can you get to appointments?**  
Can you have a car on campus? Is there public transit? Is there college organized transportation? Uber?
- Where can you get your flu shot?**

### Classes

- Introduce yourself early in the term**  
If you need accommodations from professors later on, it's good for them to know you
- Look into class accommodations such as notetakers and extensions**
- Make sure to check with each professor if they require Doctors notes for absences or extensions**
- How many classes can you realistically handle**  
There's no shame in a decreased course-load

### **Potential CF Scholarships**

- Boomer Esiason Foundation
  - AbbVie
  - Vertex
- CF Scholarship Foundation
- The Bonnell Foundation

**\*\*Remember you can take college at your own pace and don't worry about everyone else. It's a great achievement to manage CF and college, you got this!!**

# CF COMMUNITY NEWS

## SHANNON MAKES A DIFFERENCE!

SHANNON (AGE 14) IS ACTIVELY HELPING TO IMPROVE OUR PLANET. SHE TAKES ALL HER EMPTY MEDICINE BOTTLES AND COLLECTS SOME FROM FAMILY AND FRIENDS. SHE THEN CLEANS THEM AND HAS FOUND A LOCAL VETERINARIAN OFFICE TO DONATE THEM TO INSTEAD OF JUST TOSSING THEM. WELL DONE SHANNON!  
#REDUCERECYCLEREUSE



## LOCAL TEEN W/CF ATTENDS THE CF FOUNDATIONS TEEN ADVOCACY DAY!

"I ENJOY BEING INVOLVED WITH TAD, THIS IS MY 2ND YEAR. I LIKE HOW INFORMATIVE IT IS AND REALLY LIKE THE TOPIC THIS YEAR!! THE PASTEUR ACT IS SO IMPORTANT AND I LIKE KNOWING THAT I'M HELPING."  
HANNAH IS ALSO A MEMBER OF OUR CF PFAC



## THE BEST NEWS!

MAREN STARTED ON TRIKAFTA, WHICH WAS APPROVED BY THE FDA FOR AGES 6 AND UP! IF YOU WANT MORE INFORMATION ABOUT TRIKAFTA PLEASE CONTACT YOUR CF CARE TEAM.



## WE ARE GETTING VACCINATED

THE CF COMMUNITY IS ROLLING UP THEIR SLEEVES TO GET THE COVID 19 VACCINE. VACCINES ARE AVAILABLE AT NO COST TO EVERYONE OVER THE AGE OF 12! IF YOU HAVE QUESTIONS ABOUT THE VACCINE PLEASE CONTACT YOUR CF CARE TEAM OR CALL 211.



**KERRI IS BUSY TRAINING FOR  
THE BOSTON MARATHON!**

"I am a person with CF. I was diagnosed when I was 5, I'm now 40 :). I also have a sister with CF. I'll be running the Boston Marathon for CF. If you want to follow my training I'm on Instagram @cfmarathoner. My team fundraising is benefiting the Mass General Cystic Fibrosis Center. It will be my 7th marathon. As larger group, between the MA General Group and CFF MA, there are 10 runners with CF participating in the marathon." Best of Luck Kerri!

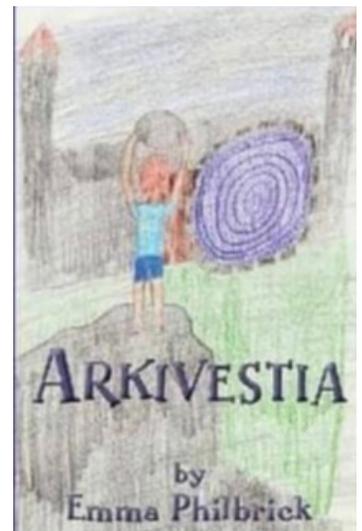


**CONGRATULATIONS!**  
CONGRATS ROSIE ON YOUR  
GRADUATION FROM CLARK  
UNIVERSITY WITH A BACHELORS  
DEGREE IN SOCIOLOGY AND PUBLIC  
HEALTH.



**LOCAL AUTHOR W/CF GETS BOOK  
PUBLISHED!**

Congrats to Emma on writing and publishing your first book! Emma's dream was to get a book published, so thanks to The Make A Wish Foundation, her wish came true! She will even have her own Book Signing on July 31st!!



# SUMMER RECIPE

This middle-eastern themed dish is a favorite from Paula Garvey and her family

## Chicken and Figs

2 chicken fillets, cut in slices

1½ teaspoons kosher salt,

1 cup chopped onions, peeled,

½ cup dried figs, quartered

⅛ teaspoon freshly ground black pepper

½ cup white wine

2 tablespoons maple syrup

3 tablespoons balsamic vinegar

½ cup chicken stock, and additional ½ cup if not using wine

1 tablespoon fresh thyme leaves

1 tablespoon garlic infused oil ( or olive oil and 1 crushed glove of garlic)

Salt and pepper to season



1. Heat oil on pan. Sear chicken until lightly brown.
2. Add onion and figs (add garlic if needed). Sauté for 3 minutes.
3. Add wine, bring to boil and reduce until it evaporates.
4. Add thyme, balsamic vinegar, and maple syrup (this will caramelize).  
Stir over heat for 3 minutes, add chicken stock, bring to boil.
5. Season with salt and pepper
6. Serve on a bed of couscous or rice. Enjoy!

This simple recipe might need some ingredients that you don't have in your pantry, but is worth the extra effort for a special occasion.  
Also, figs are naturally high in dietary fiber!



# UPCOMING EVENTS



## Seacoast Safari CF Cycle for Life - Virtual

July 17, 2021

## PLEASE JOIN US IN RAISING AWARENESS OF CF ISSUES.

If you are interested in getting involved in CF Advocacy please email Tim Guidish at [tim@reidscrew.com](mailto:tim@reidscrew.com) or Paula Garvey at [pgarvey10@gmail.com](mailto:pgarvey10@gmail.com) to sign up for advocacy alerts <https://act.cff.org/tYteTfQ>



### Advocate

Help raise awareness and inspire action for people with CF

## Start Advocating Today

To ensure that the CF community receives support from federal and state decision makers across the country, the CF Foundation provides many advocacy opportunities.

### Let policymakers know how they can help people with CF

You have the power to inspire action and help shape public policy. Taking action on behalf of the CF community only takes a few seconds.

TAKE ACTION NOW

### Conduct policy advocacy in your local community

Advocating for policies that help people with CF is a continuous effort that begins -- and is highly effective -- at home.

ENGAGE YOUR LOCAL POLICYMAKERS

### Get alerts about new advocacy actions

You'll receive periodic updates about upcoming legislation and informational webinars, how to contact members of Congress, and how to get further involved in our advocacy community.

SIGN UP FOR ALERTS

DHMC CYSTIC FIBROSIS  
PATIENT FAMILY ADVISORY COUNCIL

# PERSPECTIVE PARTNERSHIP DHMC CF PFAC

## CHECK US OUT



@nh\_cf\_pfac



New Hampshire Cystic  
Fibrosis Family and Friends



@nh\_cf\_pfac

AS PATIENTS, FAMILY MEMBERS, CAREGIVERS, AND CF CLINIC STAFF, WE EACH VIEW CF FROM A DIFFERENT ANGLE. THE DHMC CYSTIC FIBROSIS PATIENT FAMILY ADVISORY COUNCIL BRINGS PEOPLE TOGETHER ACROSS OUR CF COMMUNITY TO ADD THEIR PERSPECTIVES, TEAMING UP TO ENHANCE PATIENT CARE AND QUALITY OF LIFE.

Consider sharing your unique perspective with the DHMC CF PFAC. Options include, but are not limited to, participating in a short term project, sharing your ideas for a newsletter article, and joining PFAC long-term. Interested in getting involved?

Email Paula at: [nhcpatientfam@gmail.com](mailto:nhcpatientfam@gmail.com).

### **Thank-you to our Newsletter Team**

Emily Dutille, Paula Garvey, Rosie Garvey, Kelsey Prendergast, Jennifer Stover and Sarah Vooris for your work on this newsletter, and thank-you to everyone who contributed! If you would like to join the Newsletter team or have ideas for articles please email us.

### **DHMC CF PFAC members**

Jack Burnham, Nicole Cluff, Lynn Feenan, Paula Garvey, Rosie Garvey, Tracy Gendreau, Kate LaMare, Denise McCloat, Torie Miele, Kelsey Prendergast, Kathy Sabadosa, Ashley Shortt, Jessica Skelton, Jennifer Stover, Sarah Vooris and Hannah Vigeant