

# The December Download

## NOTES AND STORIES FROM YOUR ADULT CYSTIC FIBROSIS PATIENT & FAMILY ADVISORY COUNCIL

The Stanford Adult CF Patient & Family Advisory Council serves as a bridge between the patient community and the clinic. Our goal is to identify and address challenges to a high quality patient/family partnership with the provider, drawing from our expertise in living with and managing a highly complex chronic disease. We aim to represent our fellow patients and loved ones as CF standards evolve in the era of highly effective modulators.

## The Ultimate CF Center Winter Staff Quiz

	<b>Favorite winter treat?</b>	<b>When was the last time you went ice skating?</b>	<b>Love it or hate it? "All I Want For Christmas Is You"</b>	<b>Is Die Hard a Holiday movie?</b>
Alicia Mirza MD	Cinnamon rolls for breakfast with my family in Michigan	On the roof of the Cosmo in Vegas about 7 years ago	Quite neutral	Of course!
Cathy Hernandez CF Research	Candy Canes, anything sweet!	About 25 years ago in Oregon	LOVE	No
Denise Kwong Pharmacist	Pow day on the slopes	Last year in South Lake Tahoe	LOVE	YES
Elika Rad Nurse Practitioner	My daughter's Peppermint chocolate swirl cookies!	10 years ago in Lake Tahoe	If they didn't start playing it in stores early October, I would have loved it!	I guess it makes it so, since it's set during Xmas time?
Emily Yelencich Dietician	A fire in the fireplace on a rainy day!	About to go tonight. But before...probably 2010	Love (makes me think of Love Actually)	Die Hard is definitely a holiday movie
Gauri Pendharkar Respiratory Therapist	Hot chocolate with marshmallows	very long ago	love	NO
Jennifer Kwok Respiratory therapist	Cakes & pies	10 years ago	Love	No
Jennifer Mori Respiratory therapist	Hot Caramel Apple Cider with whip cream	5 years ago in San Mateo holiday ice rink with the kids	Love	YES
Joanna Nelson Infection Disease MD	Hot chocolate	so long ago I can't remember	LOVE	No

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Kate Yablonsky Social Worker	Hot toddy!	I am a full-blown hockey mom so...earlier this week.	LOVE	YES
Kristel Fallon Nurse Coordinator	Any kind of pie with vanilla ice cream	9 years ago, but I prefer roller skating.	LOVE	YES! "Yippee-ki-yay!"
Meg Dvorak Social Worker	Eggnog latte	It's been a while—definitely pre pandemic	LOVE	YES
Meredith Wilstie Nurse Practitioner	Snow days	Not since I lived next to a frozen pond, so ~ 10 years	Love	No
Patricia Morales Patient Care Coordinator	Anything with eggnog (deserts, coffees and cocktails)	Downtown San Jose, X-Mas in the Park 10 years ago	LOVE	YES
Paul Mohabir MD	Pajamas and home movies	20 years ago	Undecided	No
Theresa Kinney Nurse Coordinator	Hot apple cider	When I was 15??	Only Mariah Carey's version!	Yes, of course!!
Yelizaveta Sher Psychiatrist	Hot chocolate	probably 6 years ago and I fell and broke my wrist. I really should go back!	Love it	No! But you know what is - the ultimate holiday Soviet movie "s legkim parom" :-)

## The Savvy CF Traveler: Tips for a Seamless Holiday Trip

- Let the clinic know you are traveling, especially if you are going to an unfamiliar or out of state location. They can also provide you with a letter for TSA agents who get curious about your equipment or medications.
- Make sure you have your medications stocked up a week or two before you leave. Keep a list of your regular medicines + insurance card on your phone (or have the MyHealth app) in case you need to refill meds while away.
- Sometimes you might have to leave your Vest at home, so make sure you have a lightweight alternative like the Aerobika. Talk to our respiratory therapist for options.
- Use a pill day planner to minimize the number of bottles you have to bring with you (for shorter trips). If travel throws you off your routine, set reminders on your phone for crucial medications.

- Are you taking Trikafta or another modulator? Bring a few servings of your fatty snacks so you don't miss a dose on the road. For instance, throwing a bag of nuts in your backpack can do the trick.
- Have no shame about maximizing your comfort. Bring a favorite blanket and pillow. Bring your favorite pajamas or fuzzy socks. Pack comfy footwear like slippers, flip-flops, or tennis shoes.
- Charge up your devices in advance. Download your movies or ebooks. Bring a good mask, in case you're seated next to a person with flu-like symptoms. And remember: pack your chargers!
- And finally - none of this is a replacement for recommendations from the clinic. Always put their medical advice first.

## The Artist's Corner

### Can we talk about the Holiday Blues?

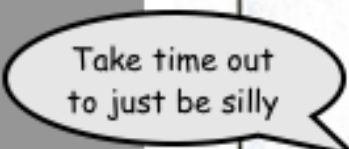
Many people can experience feelings of anxiety or depression during the holiday season. The holiday blues are temporary feelings of anxiety or depression associated with extra stress, unrealistic expectations or even sentimental memories that accompany the season. Some people can be at risk for feelings of loneliness, sadness, fatigue, tension, & a sense of loss. The most important thing is knowing that being alone for the holidays is not a reflection of your worth, it is merely a reflection of circumstances, and it will pass.

### Here are some tips to counter those blues:

- **Volunteer** at an animal shelter: Sitting with shelter dogs and giving them walks along with one-on-one attention is an option that is mutually rewarding. Comforting the dogs & cats during New Year's Eve fireworks is also a wonderful way to spend your night. Staff is limited during the holidays, so volunteers are needed. (I'm a dog lover, can you tell?)
- **Set a budget.** Do not overextend yourself financially. If you cannot afford gifts, make cards for your loved ones instead. If you cannot send cards or gifts, text your loved ones. Your sincere thoughts are worth a lot. Let people know how you feel about them.
- **Create** a holiday group text, or Zoom with your family or your friends.
- **Bake** something for your neighbors (even if you don't know them). Everyone loves brownies or cookies!
- **Watch** funny movies. Listen to music & enjoy a disco minute!
- **Visit** the beach or go online & check out the Monterey Bay Aquarium live cams! Being around water gives us a sense of awe and lets us feel like we're part of something bigger than ourselves.
- **Grow** your own traditions: Traditions can be unique to you & as simple or elaborate as you want. It could be a morning walk on the beach or playing games with friends.

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Tips to Beat the  
Holiday Blues



By: Angela Nida

## Gauri's Cozy Fall/Winter Recipe

### Ingredients:

- 2 Tbsp unsalted butter (can use olive oil or other oil of choice)
- ½ Tsp black ground pepper
- 4 Tbsp finely chopped onion (I prefer red onion)
- 1 Lb cut butternut squash cubes
- Salt to taste
- ½ Cube Vegetable Bouillon
- 1 Tbsp cream
- 1 Tsp chopped parsley (for garnish)



### Directions:

1. Boil the butternut squash cubes in enough water just to cover the squash. Add a dash of salt. Bring to a boil and simmer till the squash is cooked (check with a knife). Take off the stove and let it cool completely.
2. Once cooled, blend to a puree and keep aside.
3. Heat the butter in a saucepan, then add pepper and the chopped onions. Sauté on medium heat until onions look transparent.
4. Then add the butternut squash puree, salt and the bouillon cube. Bring to a boil.
5. Turn the heat off and serve in individual bowls. Add a dash of cream. Garnish with
6. chopped parsley. Enjoy with toasted bread!

## About Your PFAC

The Stanford Adult CF Patient & Family Advisory Council serves as a bridge between the patient community and the clinic. Our goal is to identify and address challenges to a high quality patient/family partnership with the provider, drawing from our expertise in living with and managing a highly complex chronic disease. We aim to represent our fellow patients and loved ones as CF standards evolve in the era of highly effective modulators.

We want to grow, so If you're interested in sitting in on a meeting or joining the PFAC, contact Kate Yablonsky at [kyablonsky@stanfordhealthcare.org](mailto:kyablonsky@stanfordhealthcare.org) or (650) 444-6512 to learn more! Any patients or family members from the CF Adult Clinic are welcome to become Advisory Group members. Not only are family members welcome to join, they are encouraged.