

# Cystic Fibrosis Center Newsletter

## Reminders

### Flu shot

Its time to get your yearly flu shots. CF clinic will not have shot available, so please make it a priority to get your flu shot at your PCP office or a local pharmacy.

## Back to School Tips and Tricks

Summer almost and it's time to start thinking about going back to school. Some reminders to help you start the school year off right:

1. Avoid those drinking fountains! Be sure to take bottles of water to school so you aren't tempted to stop at the drinking fountain when you are thirsty.
2. School forms for enzymes and medications- friendly reminder to get these to us early.
3. Don't forget to bring snacks! Here are some ideas for quick and easy high calorie snacks
  - Trail mix
  - Peanut butter and fruit or crackers
  - Pretzel and hummus snack pack
  - Cheese and nuts snack pack
  - Pre-made guacamole cups with tortilla chips and vegetables
  - Peanut butter and jelly sandwich
  - Yogurt, fruit, granola- check out pre-made yogurt plus mix-ins such as Chobani® Flip®



## Yearly labs

Reminder to get your yearly labs drawn before the end of the year. Summer is a great time to take care of this so you don't have to work around school schedules.

You can visit any OSF outpatient facility that draws blood or come to the hospital for these tests.

Be prepared to tell the lab exactly what orders you need drawn so things are not missed. Here is the list you will need to share with the lab.

CMP            CBC  
 IGE level    Vit A, E, D

If over 10 yrs old, you will need to get your Oral Glucose Tolerance Test if you have not been diagnosed with CF Related Diabetes.

## Farewell from Marie

As I look back and reflect on my 30 years with the CF Center I think about what it was like when I began. There was Albuterol and enzymes, some vitamins but not CF specific vitamins. The vest was the size of an oversized suitcase, a very heavy oversized suitcase! IV antibiotics could only be administered in the hospital for weeks at a time and we didn't have as many choices for oral antibiotics.

I remember exactly where I was when I heard on the radio the CF Foundation was announcing the discovery of a new medication, Pulmozyme. We take it for granted now, but to witness the way it thinned the mucus and how people felt once they took it was a game changer.

Official tobramycin, or TOBI soon followed along with Hypertonic Saline. The pancreatic enzymes experienced a revolution with increased doses and more brands to choose from, not to mention the CF vitamins.

And now Kalydeco, Orkambi, Symdeko, and Trikafta! Wow!  
But I believe the best is yet to come.

These discoveries and new treatments were only possible with the help of the CF Foundation. The CF Foundation based in Bethesda MD, realized very early that to make a difference, information and discoveries would need to be shared with the whole CF community including medical personnel, scientists, patients and families. That idea is why we are where we are today. Centers from around the world working together, sharing information and ideas. It's pretty cool to have been a small part of something so important.

It has been a great honor and privilege to work with you and your families at the CF Center. While part of me is sad to leave, I am comfortable in knowing that you are in good hands with Sarah and the CF team.

P.S. If you would like to learn more about the official history of CF, I highly recommend the book *Breath from Salt*. It is very comprehensive and informative. Thank you to Dr. Soriano for recommending it to me.

## Summer Recipe

### Esquites (Mexican Corn Salad)

**Prep Time:** 5 minutes **Cook Time:** 15 minutes **Total Time:** 20 minutes **Servings:** 4

#### Ingredients

- 2 tablespoons butter
- 3 cups corn (about 4 ears), cut from the cob (canned or frozen works too)
- 1/2 jalapeno, seeded and finely diced
- 3 tablespoons mayonnaise
- 1 glove garlic, grated
- 2 green onions, sliced
- 1 handful cilantro, chopped
- 1 lime, juice
- 2 tablespoons cotija (or feta), crumbled
- chili powder to taste

#### Directions

Melt the butter in a heavy skillet over medium-high heat.

Add the corn, toss and let it sit cooking until charred, mix it up and let it char again, about 6-10 minutes.

Add the jalapeno, saute for a minute and remove from heat. Mix everything and serve warm or at room temperature.

