

# CF Connection

Winter/Spring 2018

University of Florida Pediatric Pulmonary Center

## Get to Know Erica!

You probably know Erica, our Medical Assistant in clinic, is cheerful and has a great sense of humor! But did you know she has seven dogs and she used to be a corrections officer? Read on for more fun facts!

**How do you like to spend your free time?** I love to garden and spend time outdoors with my husband Tony and my daughter Alyssa, who's in 6<sup>th</sup> grade. I also like to go to the beach.

**Tell us about your family.** I'm the oldest of six kids. My family moved from Indiana when I was a Junior in high school and I wasn't happy about that!!! But later all of my family (except one sister) moved back to Indiana. My husband, daughter, and I are very close. We have seven dogs – including two bulldogs named Bonnie and Clyde and a Jack Russel, Molly, who is really my second baby.

**Where are two places you'd like to visit?** My dream vacation would be to visit Rome. I'd also love to go to the Blue Ridge Mountains.

**What do you wish you were better at doing?** Being creative. But I am great at organizing!

**Why did you decide to become a nurse?** I've always wanted to be a nurse so I could help people. Before this position, I worked as a CNA in a nursing home and I was a corrections officer for four years.

**What's a fun fact about you?** I marched in the Macy's Day Thanksgiving Parade in New York City with my high school color guard!

**What's your spirit animal?** A goat – they are loud, stubborn, and crazy like me!

**Who inspires you to be better?** My daughter Alyssa. My biggest goal right now is to help prepare her for the "real world" and help her graduate.

### Flu Shot—It's Not Too Late!

It's important for people with CF and their family members to get the flu shot every year. It's not too late if you haven't already gotten it (ask your primary care doctor or local pharmacy). People with CF can develop severe pneumonia from the flu. Please let your CF care team know if your child has flu-like symptoms such as fever and body aches.

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### We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 4 or e-mail them to [hillajb@peds.ufl.edu](mailto:hillajb@peds.ufl.edu).



## What to Bring to the Hospital

If your child is going to be admitted to the hospital, here are some items to bring along. It may be helpful to keep a copy of this list in your child's suitcase.

- ✓ Insurance cards and other important legal documents (such as custody papers if needed)
- ✓ Airway clearance devices (Acapella®, Vest®, in-Courage™ system)
- ✓ Medications (especially if using Creon enzymes since the hospital does not carry this brand) – bring in the original prescription bottle
- ✓ Extra snacks, microwave meals (microwave and refrigerator are available)
- ✓ Comfy clothes –don't forget socks, slippers, pajamas, robe
- ✓ Exercise/gym clothes and shoes for physical therapy
- ✓ Toiletries
- ✓ Activities such as books and games
- ✓ Electronics such computer, cell phones (and chargers )
- ✓ Favorite pillow, blanket, stuffed animal
- ✓ Schoolwork
- ✓ Earplugs and/or eye mask



## Easy Fudge Recipe

*These are so easy and delicious!!!*

### Ingredients:

- 1/2 cup coconut oil
- 1/2 cup cocoa powder
- 1/2 cup smooth nut butter (such as peanut or almond)
- 1/4 cup honey or maple syrup
- 1/2 teaspoon vanilla

### Instructions:

1. Melt coconut oil.
2. Mix all ingredients in blender until smooth.
3. Pour into silicone muffin cups (use paper liners if using a metal muffin pan). Fill about 1/2 inch each.
4. Freeze until firm (about 10 minutes) and enjoy!!!

*Makes about 10 servings—200 calories each!*

## Health Apps to Help Manage Care

Managing medications and treatments for CF can be overwhelming. The good news is that technology can help! Many apps are available for Apple and Android users to help manage CF care. Two free apps that many people find helpful are MangoHealth and CareZone.

With Mango's app, users enter their medications or supplements, timing, and doses. Mango can remind you when it's time to take your medication or check your blood sugar. It also automatically alerts you to potentially dangerous interactions between medications, or with food and drink. The app also includes a personal health journal. It has an in-game currency users can earn by taking medications on time and a leveling up system. By leveling and saving up, users can unlock real-world rewards at stores like Target.

CareZone makes it easier to stay organized and effective. From your computer, smartphone, or tablet you can safely organize files, contacts, and medications, and coordinate with family and other caregivers using a shared calendar and journal.

## What's the Best Order to Take Medications?

Did you know that there is a certain order of medication use that should be followed for the most effective airway clearance? Read on to learn more!

### Therapy #1: Bronchodilator

**What?** albuterol (Proventil®, ProAir®, Ventolin®), levalbuterol (Xopenex®)

**How?** Inhaler or nebulizer

**Why?** To open up the airways by relaxing the muscles around them. This helps to widen the airway and make air flow easier into and out of the lungs. This assists other medications getting into the lungs better, and mucus to move out easier.

### Therapy #2: Hydration

**What?** hypertonic saline (Hypersal®, Pulmosal®)

**How?** nebulizer

**Why?** Draws water onto the airway surface making airway secretions less thick and sticky, and helps cilia have enough room to move. Cilia are little hair like structures whose job is to move the mucus by moving together in a waving pattern. Cilia help move the mucus up the system of airways toward the larger airways where mucus can be coughed out.

### Therapy #3: Mucolytics

**What?** dornase alfa (Pulmozyme®)

**How?** nebulizer

**Why?** Making mucus less sticky and thick will make it easier to move the mucus and cough it up and out. Less mucus means less chance for more bacteria to grow in the lungs.

### Therapy #4: Airway Clearance Therapies

**What?** Moving mucus up and out!

**How?** Chest percussion, OPEP (AerobiKa®, Acapella®, Flutter valve®) PEP device

Breathing techniques: autogenic drainage, active cycle breathing, huff cough

Vest systems: TheVest®, inCourage®, Smart Vest®

**Why?** Moving mucus up and out of the lungs is the most important part of airway clearance therapies.

### Therapy #5: Inhaled Antibiotics

**What?** aztreonam (Cayston®), tobramycin (TOBI®, TO-BI® Podhaler™, Bethkis®), colistimethate (Colistin®)

**How?** nebulizer

**Why?** Antibiotics help to kill the bacteria that can grow in the mucus. It's important to take ALL of the antibiotics that the doctor has prescribed.

### Therapy #6: Corticosteroids (for asthma diagnosis)

**What?** Inhaled steroids: budesonide (Pulmicort®), beclomethasone (Pulmicort, QVar®), fluticasone (Flovent®, mometasone (Asmanex®) ciclesonide (Alvesco®)

Inhaled corticosteroid and long acting bronchodilator: (fluticasone and salmeterol (Advair®), budesonide and formoterol (Symbicort®), fluticasone and vilanterol (Breo®), mometasone/formoterol (Dulera®).

**How?** inhaler/nebulizer

**Why?** Airways can be swollen from mucus and infections. Corticosteroids will help reduce swollen inflamed airways. Be sure to rinse the mouth after taking them!

## Great Strides Walk—Coming to Gainesville!

It's the 30<sup>th</sup> anniversary of Great Strides – the CF Foundation's largest fundraising event! Each year, more than 125,000 people participate in over 400 walks across the country to support the Foundation's mission to cure CF and raise awareness of this disease. Please join us in Gainesville on April 14<sup>th</sup> or find another walk in your area to help raise money to end CF. For more information, please visit: <http://fightcf.cff.org/>

# University of Florida Pediatric Pulmonary Center

## Family Corner

### MyUFHealth (MyChart)

The patient portal (no, we are not beaming you away!) here at UF Health is a great way to stay in touch with your healthcare team. We used to call it MyChart, now we call it MyUFHealth.

You need an email account and an activation code to get started.

Follow this link: <https://ufhealth.org/myufhealth-login> to

- ✓ Request an Activation Code
- ✓ Sign up
- ✓ Login

In MyUFHealth you can:

- ✓ Email with your healthcare team
- ✓ Look up test results
- ✓ Request new prescriptions
- ✓ Manage appointments
- ✓ Look at and pay bills online

### Getting Around the Hospital

If you are new to UF Health it can be hard to find your way around. Check out the new color-coded First Floor Map: <https://ufhealth.org/sites/default/files/UF-Health-Shands-Hospital-north-campus-color-coded-first-floor.pdf>

To find your way around, look for a number and follow a colored path. Copies of the maps are at all entrances. Look for where you need to go, check its number and follow the colored path – we hope this makes coming here a little less stressful, especially if you are new.

We would love to hear from you about MyUFHealth and your experience with the maps. Email me with your feedback: aminey@peds.ufl.edu

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