



just Breathe...

A Seasonal Newsletter from the Cystic Fibrosis Team at Phoenix Children's Hospital

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Fall

What's New

The US Food and Drug Administration (FDA) has approved the use of lumacaftor/ivacaftor (Orkambi®) for children with cystic fibrosis ages 2-5 years, who have two copies of the F508 del mutation.



The FDA first approved lumacaftor/ivacaftor in 2015 for CF patients ages 12 and older who have two copies of the F508del mutation. In 2016, the FDA expanded that approval to people with CF ages 6-11 years.

A Phase 3 study evaluating the drug for children ages 12 months to less than 24 months is planned to start later this year.

In people with two copies of F508del, lumacaftor/ivacaftor improves lung function and significantly reduces the rate of pulmonary exacerbations.

[Learn More](#)

Recipe Corner

This high calorie treat will be loved by your entire family.

Spiced Nuts

- 1 tbsp extra-virgin olive oil
- 1 tbsp pure maple syrup
- 1 garlic clove, minced
- 1 tsp cumin seeds
- 1 tsp nigella seeds
- 1 tsp oregano, dried
- 1/8 tsp cayenne pepper
- 2 1/2 cups unsalted assorted nuts
- 1/2 tsp fine sea salt
- 1/2 cup pecan halves
- 1/2 cup walnut halves
- 1/2 cup skinned hazelnuts
- 1/2 cup shelled pistachios
- 1/2 cup natural almonds



Directions

- Position a rack in the center of the oven and preheat to 350°F.
- In a large bowl, mix the oil, maple syrup, garlic, cumin, nigella seeds, oregano, and cayenne.
- Add the nuts and mix well to coat the nuts.
- Sprinkle and toss the nuts with the salt. Spread the nuts on a large rimmed baking sheet.
- Bake for ~ 20 minutes. Stir occasionally to bring the nuts that cook more quickly around the edges into the center, until the nuts are lightly toasted and glazed.
- Let cool on the baking sheet.
- Break apart the nuts.
- The nuts can be stored in an airtight container at room temperature for up to 10 days.

Nutritional Information (Serves 8)

Amount Per Serving: Calories: 470

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Most CF patients are currently on Specialty medications. These are medications that need special authorization from your insurance company because they tend to be expensive.



Some of the most common Specialty meds are Pulmozyme, Tobramycin (Tobi Podhaler, Tobi, Bethkis, Kitabis), Cayston, Orkambi, Symdeko and Kalydeco.

If you are prescribed these medications, your provider needs to know if you do not receive them.

Frequently, they require a prior authorization through your insurance and then it typically needs to be filled at a Specialty pharmacy.

The process could take one to two weeks. In some cases it can take up to a month if a special appeal is needed.

It is very important that you let us know if you have not received the medication after a few weeks and we will investigate the problem.

Together we can make sure you or your child have all the appropriate medications needed.



Compass Can Help

Many cystic fibrosis patients and families



CF Peer Connect Expands to Family Members

face complicated issues related to getting the care they need. CF Foundation Compass means no one has to do it alone.

[Learn More](#)

CF Peer Connect, a peer support program for people affected by CF, is now open to family members ages 16 and older. Participants can talk with and learn from another person who has experienced similar situations.

[Request a Peer Mentor](#)



AHCCCS CRS Program is Changing

Starting October 1, 2018, most CRS members will be enrolled in new AHCCCS Complete Care (ACC) plans and will be able to receive their care at any provider in their new ACC plan's network, allowing for choice by families as to where their children will receive their care.

Phoenix Children's is an in-network provider with five of the seven ACC plans. These plans include: Care 1st, Steward Health Choice Arizona, Banner University



A message from the CF Family Advisory Council

The CF FAC is hosting a Family Education Day on August 25 for families, friends or caregivers of patients with Cystic Fibrosis. The half-day program will include topics on the state of CF and Research, Transitioning to Adulthood, Exercise, Dealing with taxes and being organized, and a panel of peers for discussion. Registration starts at 8:30 a.m. at the Melvin L. Cohen Conference Center at Phoenix Children's Hospital. (Please RSVP to Chris Verdugo 602-933-0775.)

Family Care, Mercy Care, and UnitedHealthcare Community Plan.

All Phoenix Children's providers, including those that previously provided care to CRS patients offsite at the MSIC, will be providing care to CRS patients onsite at Phoenix Children's.

If you need more information or to schedule an appointment, please contact Phoenix Children's Care Management at 602-933-KIDS.

Are you interested in participating in the Family Advisory Council? We're accepting applications at the Family Education Day or you can inquire during a clinic visit. We help create events like the Family Education Day, implement a CF self-identifier badge you can choose to use at the Hospital to assist in cross-contamination avoidance, and work to improve both the in- and out-patient experience by providing feedback to the hospital. We want your voice and perspective!



Your Resilient Mindset

By Dr. Jeanette Smith (AKA Dr. J)

I'm repeatedly impressed by the resiliency shown in individuals with CF and their families. You already have so many of the wonderful skills needed for Resilience. To prove it to yourself, look at the basic components of Resilience. Think about a time or two when you demonstrated your skills with resilience.

Resilience = Behaviors, Thoughts, and Actions that Help People Adapt Well with Adversity, Tragedy, and Other Sources of Stress.

Some of the major components of resilience are:

Allowing Oneself to Experience Emotional Pain and Sadness

Resilience isn't about avoiding pain and sadness, as those feelings are a part of being human. When we try to block these feelings, they'll come out in other ways. When we accept our sadness as a part of life, knowing that it is one of the many waves of emotion that will change over time, then we are able to find healthy ways to cope with all of

these feelings. Remember, the CF clinic is here to help you! Just ask.

Be Flexible and Accept that Change is a Part of Living

We make plans. We expect things to be a certain way. Then the unexpected happens. We learn over and over that being

Act on What Can be Changed Rather Than Detaching from Stresses

Rather than allowing the unexpected to derail us completely, we accept what we can't change and work to change what we can. For example, growing to accept a diagnosis of CF and learning how to organize all of the daily treatments to keep as healthy as possible.

Confidence in One's Ability to Solve Problems

You're facing another challenge. Now what? Remember, you've faced this feeling before and somehow managed to work through and solve the problems in each situation. You can do it again!

Make Connections with Others

Reach out to others with similar interests and values. Join a book club, mechanics class, swim class, hiking club (ask us about CF Activity Scholarships). Infection control guidelines make it especially challenging to talk with others with CF. Make connections virtually through the national Peer Mentor program run through the CF Foundation. Parents and individuals with CF age 16 and over can request a mentor who has gone through similar experiences. Visit: cff.org/PeerConnect.

Find Meaning in Life - A Purpose

Allow yourself to think about your values, what is important to you. Then think about goals and behavior that are consistent with living that valued life. Start engaging in small behaviors toward your goals each week.

Now that you've seen the many areas where you have already demonstrated resilience, know that you can build upon that.



[Promenade](#)

Upcoming Events

[October 6: CF Climb at ASU's Sun Devil Stadium](#)

[November 30: 65 Roses & Wine Gala in Downtown Phoenix](#)

[December 8: Scottsdale Great Strides at the](#)

More Details to Follow:

November: Spouse/Couples workshop for Adult Partners or Parents of Children with CF

Resources

[The Emily Center at Phoenix Children's Hospital](#)

[Live2Thrive](#)

[CF Compass](#)

[HealthWell](#)



"A journey of a thousand miles begins with a single step."

-author unknown



Cystic Fibrosis at Phoenix Children's Hospital

1919 E. Thomas Rd. Phoenix, AZ 85016

Main Number: 602-933-1000

Pulmonary Department: 602-933-0985

Psychology Department: 602-933-0414

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