



# just Breathe...

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

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## What's New

The US Food and Drug Administration (FDA) has approved a third drug from Vertex Pharmaceuticals directed at an underlying cause of cystic fibrosis (CF).



The new treatment combines ivacaftor (*Kalydeco*), with tezacaftor. It will be sold under the brand name *Symdeko*. *Symdeko* is indicated for the treatment of CF in people aged 12 years and older, who have two copies of the F508del mutation or who have at least one mutation that is responsive to tezacaftor/ivacaftor.

Ivacaftor enhances the function of the CFTR protein once it reaches the cell surface to improve the transport of salt and water across the cell membrane. This helps hydrate and clear mucus from the airways. Tezacaftor increases the amount of mature CFTR at the cell surface by targeting the processing defect of the CFTR protein.

The tezacaftor/ivacaftor combination was studied in two phase 3 trials (EVOLVE and EXPAND). This involved about 750 people with CF.

[Learn More](#)

## Recipe Corner

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

## No Bake Peanut Butter Bars

- 3 cups old-fashioned oats
- 1 ¼ cup honey
- 2 (16 ounce) jars natural peanut butter
- 1 cup dried fruit (raisins, cranberries, etc.)
- 1 cup crushed nuts (almonds, cashews, etc)
- 1 tablespoon salt

### Directions

- Combine honey and peanut butter in a large mixing bowl.
- Combine oats, dried fruit and nuts in a large mixing bowl.
- Combine dry ingredients with the wet ingredients, one cup at a time, until thoroughly mixed.
- Press into a 9x9 pan or dish. Eat right away or refrigerate overnight to let it set.



*Nutritional Information (Serves 16)*

*Amount Per Serving: Calories: 550, Fat: 32 g, Sodium: 650 mg, Protein: 15 g*

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## Tomorrow's Leaders

To engage a new generation of leaders to support its mission to find a cure for all people living with cystic fibrosis, the [Cystic Fibrosis Foundation](#) is

launching *Tomorrow's Leaders*, a program designed to offer like-minded young professionals networking and leadership development opportunities while supporting those living with CF.

For an annual membership fee of \$65, members gain access to unique programming, diverse networking, leadership opportunities, and a connection to the CF community.

[Check It Out](#)





## Please join us in welcoming Michelle Martinez, RN!

Michelle will be our new Pediatric Cystic Fibrosis Coordinator!

She has been with Phoenix Children's since 2000; and most of her career has been dedicated to Pulmonology. From 2003 to 2015, she worked with both pediatric and adult CF patients, those affected by asthma and also helped with our sleep medicine program as a coordinator for a few years. Her experience includes working in general pediatrics and in orthopedics as a nurse program coordinator for families with special needs.

Michelle looks forward to working with your family and hopefully making a difference in the lives of your children.



## A message from the CF Family Advisory Council

The CF Family Advisory Council is seeking new members.

If you are interested in getting more information or participating in FAC, please contact us at [fac@phoenixchildrens.com](mailto:fac@phoenixchildrens.com).



## Stress. It happens.

Why do some people experience better outcomes when impacted with the same stress as others?

**The answer may be in developing a Resilient Mindset.**

- Researchers have found that resilient individuals view stress as an obstacle to learn from, rather than be defeated by the stress. Resilient individuals have been shown to live longer, and they're sick less often. This doesn't mean they are able to get rid of their stress. Instead, it is about recognizing what we have control over and accepting what we can't control (similar to The Serenity Prayer). We focus our energy on situations which we have some influence.

### What can you control?

- We know that CF presents lifelong management. Maintaining our physical self-care is one of the best things we can do for stress management, yet often the first thing to go when stresses increase. Getting enough sleep is a major factor in helping ourselves cope with stress. Experts recommend we schedule 7-8 hours of sleep time each night (more for toddlers and teens). Some of the recommendations include: no caffeine intake starting in the afternoon, avoid watching television, doing work, or bringing your computer or smartphone to bed. Research has shown that electronics wake up our brain and should be avoided for 1-2 hours before bed. Laying down during the day, especially while watching television, may make it more difficult to fall asleep at night.
- Late afternoon or early evening exercise helps decrease stress and promote sleep. Ideally, the exercise would be completed 3-6 hours before you want to sleep. Exercise is also an important variable in mood management, helping decrease depression and anxiety.
- Practice relaxation techniques daily. You can breathe in a slow, deep breath and as you slowly exhale, imagine your body being a fully relaxed, limp, rag doll. Or, take a 3-minute vacation – visualize yourself somewhere (real or imagined) that

feels wonderful to you. Use all of your senses – what you see, hear, taste, smell, and feel.

- Bringing laughter and humor into your life is also stress relieving. Watching a funny show, telling jokes, or being around a friend who likes to be goofy, can all be great for stress relief. Remember to engage in playfulness, be silly, be present to enjoy the little moments in life that make you smile.
- Problem-solving is an ongoing process throughout our lives. Remember that mistakes are experiences from which to learn. If something is not working, then think about what you can do differently. For all of us, there will be obstacles and set-backs, and you'll be able to work through those as well. Remember, we're here for you, and together we can figure out how to work through life's obstacles!

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## CF Foundation Virtual Events

Designed by and for adults with cystic fibrosis and their families, virtual events provide opportunities to connect, share, and learn from peers through open and honest dialogue.



[Virtual Event Calendar](#)



## Upcoming Events

[April 22nd: Great Strides](#)

**More Details to Follow:**

*August 25th: PCH Family Education Day*

*Date TBD: Sibling Day*

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## Resources

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

[Cystic Fibrosis Foundation](#)

[CF Compass](#)





**Cystic Fibrosis at Phoenix Children's Hospital**

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