Opinion

News

From Bishop Daniel Flores' Twitter account

by Christian Mocek

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I used to wake up in the middle of the night to her coughing, a kind of cough hard to explain. It was a foe around for so many years it had a life of its own. Loud, chesty, violent and forceful. Never welcomed in our marriage, but part of it as much as the wedding rings on our hands.

In the moonlight, I watched her body recoil at the force of each cough. I watched as she curled up trying to brace her body from the pain. I watched as she straightened up, desperately reaching for air.

I felt her hand squeeze my arm. I saw her face turn red, her eyes reaching out to me as if I could do anything to stop it. As if I could do anything at all, instead of only lie there hoping one day she wouldn't wake up coughing and I wouldn't wake up next to her feeling helpless, watching as her breaths fell away.

Early in our marriage, I noticed three times when her coughing was the worst: when she exercised, when she laughed and when she slept. It was the cruelest part of her cystic fibrosis. When she was able to let go of the burdens of the moment, her illness reared its head through explosive coughing fits. Her body seizing and grasping for air. Her body reminding her that she can never let go.

My wife, Gillian, is seldom defeated and bears her illness with a strong sense of purpose and determination. Two hours a day of breathing treatments, pills to sort, endless calls with insurance companies and doctors. Her commitment to her daily regimen, her resilience and her grit match that of a professional athlete. She never fails to work the daily grind so that when a breakthrough therapy comes that can drastically improve her life, she's healthy enough to embrace it with open arms.

Last fall, much to our surprise and excitement, that day came.

In October 2019, the FDA approved a treatment for cystic fibrosis that promised transformational results. A three-pill combination of medicines appropriately named Trikafta. Approved for nearly 90% of the cystic fibrosis population, Trikafta not only stabilizes lung function — as previous generations of this type of medicine have — but it causes sometimes significant improvement.

To understand the significance of that, one must first understand cystic fibrosis. Cystic fibrosis is rare, genetic, progressive and life-threatening. Thick mucus builds up in the lungs, digestive tract and other parts of the body. Over time, this mucus

breeds infections from bacteria. The consistent infections and inflammation lead to lung damage, then eventually respiratory failure and death.

Trikafta doesn't solve the genetic mutation, but it helps the mutation function differently, helping the mucus our bodies naturally produce to become thinner and less prone to infection. This, in turn, improves the function of the lungs and other organs. In layman's terms, it effectively treats the underlying cause of the disease.

It's a privileged yet humbling thing to be given something you've so long prayed for, a thing yet unsure you would ever receive. In December 2019, we received our first shipment of Trikafta. It was as if a miracle had arrived at our doorstep. The key to a new life just sitting there in a box. A new beginning in the form of three small pills.

As one would expect, there was dancing and elation at first. We cried, we told everyone we knew, we celebrated with friends and family. Then, in the quiet of the night as the initial shock tapered to a solemn excitement, we started to internalize what this really meant. That the journey we thought we were on, that the ending we thought was already written, that the suffering we thought was in our future, was no longer a foregone conclusion.

On Jan. 16, she took her first dose of this miracle medicine that was only dreamed about when she was born. Almost immediately the effects started to take hold — as if the illness started purging from her body. Her breaths grew deeper, her laughter rang out uninterrupted, and within a month and a half, her lung function jumped 20%. Thirteen years of continual decline disappeared in a flash.

It's as if everything's changed, yet nothing has changed. Our lives go on as normal. Yet, everything is transformed. To know that Gillian will be there to see our son, Simon, off to school, to welcome him home, to make snacks for his friends and to kiss him goodnight.

I know we don't know — that's the truth of life. But we know it's possible.

And if what I have now is the ability to trust in what's possible, then I have everything. What was is not anymore, and what's left is what life can be. Knowing our book doesn't need to be written yet. Trusting the possibility that there are many,

many chapters left blank — unwritten — ready to be written as time goes on.

Not too long ago, we were walking at a park watching Simon chase after his uncle 40 feet ahead. To the right of me, I heard footsteps rapidly increasing, then Gillian blew past me sprinting straight toward Simon. She caught up to him, lifted him high into the air, both laughing as they spun in circles around the path. Both with not a care in the world, not a thought of struggle or suffering to be found.

Simply a mother and her son. A mother not coughing, not reaching for air, no longer in pain.

God is not shy in his blessing nor timid in his ability to transform lives. So often, praying for big things feels like a shot in the dark. But to pray and receive — to receive what you always hoped for — affirms that God in his love for us wants to fulfill the deepest desires of our hearts whether we know them or not.

God works in big ways, too, and what I'm most certain of after these two months is that we should never not pray for something we think is impossible because, for God, it's possible.

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