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Lymphangioleiomyomatosis

In January of 2007, I woke up in the middle of the night, coughing up blood. At the hospital, my pulmonologist was very clear that I did not have pneumonia, as I had thought for many years. While I thought he was crazy, I agreed to do the tests he suggested. On June 7, 2007, I had my first CT scan, which I planned to have reviewed at an appointment two weeks later, but on June 13, I suffered my first lung collapse. My lung was 90 percent collapsed on one side and 40 percent collapsed on the other side. The ER doctor gave me two choices: either a chest tube then and possible surgery later, or immediate surgery. Either way action was required, as I was so critical that I would have been dead in less than an hour without intervention. It was a miracle I was alive! The doctors put in my first chest tube. All they could tell me is that I had cysts in my lung. It was a whirlwind of events and emotions. The next day, with my mom, sister, niece, and pastor all in my room, the pulmonologist finally arrived. As he described what he thought I

had; I felt as though I had been hit by a brick wall. He continued to explain this rare disease as I dried my tears and the fog cleared. He asked, “Are you okay?” My reply was instant and life changing. “God’s got me! Yes, God's got me.” With this new revelation of lymphangioleiomyomatosis (LAM) I was given three to five years to live, and lots to do to address this disease. My family and my church family were there caring for me from the very beginning!

The insanity of dealing with a rare disease that is debilitating, progressive, has no treatment, no cure and has already crippled your life is hard to describe. Before being placed on oxygen, I was often bed ridden. I relied heavily on my mom and church family for meals, cleaning, rides, and more. I had gone from being independent, pursuing a successful career, and doing my own thing to being dependent upon others. My needs were great, and they were met with love.

Once on oxygen, I slowly began to be able to get out and live life more abundantly. I pursued a new passion for gardening, and adopted a phrase, “gardening from the chair,” after I was given a wheelchair. For years I couldn’t load and unload the large tanks I used for longer trips, like for church and hanging out with friends, but I had help. I also had smaller tanks I often used for shorter trips to the grocery store, picking up prescriptions and such. While being oxygen-dependent is often considered a curse, I was so happy to be out of bed I really didn’t mind it so much.

By the time I was placed on high flow oxygen I was going through a large tank of oxygen every 45 minutes to an hour. Just attending church required that I bring at least four to six tanks minimum, but I was finally able to load and unload tanks on my own most of the time.

On May 9, 2018, I got the call for a lung transplant. After one of the longest nights of my life, I was wheeled into the scariest surgical room I had ever seen. I had new lungs 14 hours later.

"I cannot imagine my life without my care providers in it. I realize that I am blessed to have more care providers than most people in my situation can even imagine. Each one is a divine gift that I thank God for placing in my life. I never imagined I would need them as much, or for the many years, as they have been caring for me. Their love, aid and provision in my life have been essential to my story."

While I had been well prepared for the process, I had no way of knowing my own transplant journey would be so difficult. I was in the ICU for 23 days, in two separate comas. The first one is when I believe the "alternate reality" began. I just knew they were going to take my new lungs. I begged everyone who visited to rescue me, while I still had my lungs. This alternate reality is the only memory I have of that time. For me it was real! My delusion morphed into a belief that they were trying to kill both me and my sister. I felt that as hard as I tried, she just didn't get how serious I was.

As they decreased the drugs my mind began to clear. I still couldn't even stand, walk, eat, remember certain basic information, hold a pen, or write my name.

The physical therapists came in each day and helped me learn to walk, and even eat, again. Eating was so horribly painful I could only eat a few bites. This also made exercise and basic functioning extremely difficult. I also made great progress mentally. At first, I could not remember what day it was. Finally, I began to grasp and communicate days, times of day, names and details about life going on around me. I was released just over a month later, to a hotel nearby.

It was several weeks before I was able to make it all the way to our room. My poor mom had to push me. She also made every meal, cleaned up after me, bathed me, clothed me, got me to all my doctor appointments, did all the shopping, dishes and helped me exercise when I wasn't at pulmonary rehab. My process was insanely slow. Finally, about two months out, I ate almost a full serving of food. A couple of weeks later we were finally allowed to go home.

My first week home one of my friends from church stayed with me overnight as I needed 24-hour care. It took a few weeks, but I slowly began to care for myself. This was an incredibly painful process. When asked if I'd do it again, I quickly replied "No!"

About nine months after my transplant, I decided I wanted to try to run. After some discussion with my pulmonary rehab team, we decided to give it a try. I had not been able to actually run for almost 15 years. That day I ran for one whole minute! Elation only begins to describe how I felt! I had finally reached that place. My new answer was "Yes!" If I had to do transplant over again, I would do it. Yes, it was worth it. I am now over three years post-transplant. Without God, my donor, care providers, family, supporters, and these beautiful pink lungs I would not be alive today. ●

Lymphangioleiomyomatosis

Lymphangioleiomyomatosis, also known as LAM, is a rare lung disease that mainly affects women, usually during their childbearing years. LAM is caused by mutations in the tuberous sclerosis complex (TSC) genes. These mutations lead to growth of abnormal cells that spread by the blood stream and make their way into the lungs. Once in the lungs, these cells create holes in the lung tissue (called cysts) that can weaken breathing and the ability to take up oxygen.

- Elevated VEGF-D levels can help confirm the diagnosis of LAM without needing a lung biopsy.
- LAM causes multiple air-filled holes, called cysts, in the lungs. Often these cysts can rupture and cause air to leak outside of the lung, leading to lung collapse.
- There is a possibility that pregnancy may lead to progression of LAM, so consult your doctor if you are pregnant or considering pregnancy.

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