Nicole Seefeldt

LAM AND TUBEROUS
SCLEROSIS COMPLEX

> *"It's been hard for me to accept. Yet, I have reason to hope. The puzzle pieces for my diseases are coming together."*

I liken most of my days to boxing. If I get knocked down, I might have lost the round but not the match. As soon as I can, I'm up for the next go and ready to score the knockout.

When I was just 7 months old, I started having seizures. They arrested early, but at age 3, I was diagnosed with tuberous sclerosis complex (TSC). TSC affects me genetically by causing benign (but large) tumors on many of my organs.

Though my parents did their best, I knew I was different at a very early age. Outside of what looked like oversized freckles on my face and body, hardly anyone could tell.

In 1999, I graduated with a bachelor's degree in journalism and moved to New York. On New Year's Day 2002, I rung in the holiday with my first lung collapse. It was then that I learned of another disease, lymphangioleiomyomatois (LAM), and in 2003 I received the diagnosis.

LAM is an insidious, savage illness that acts like asthma but also secretes proteins to break down the healthy tissue around my lungs.

It acts as unpredictably as multiple sclerosis (MS)—I have periods when I'm fine and you'd never know that anything is wrong outside of my being a little short of breath. But when something goes wrong, it goes painfully wrong.

I've had multiple hospitalizations, surgeries, and even two brushes with death because of the war both diseases have waged on my kidneys and lungs. It's as though they take turns acting up.

I have remissions, plateaus, and exacerbations at any given point (much like MS or cancer). It's a particularly ugly combination and, in the case of LAM, it can be lethal. Sometimes, I have obvious warning signs something is wrong, like lung

LAM

- LAM is a progressive lung disease that usually strikes women during their childbearing years, which results in the destruction of healthy lung tissue caused by cyst formation and abnormal growth of smooth muscle cells not usually found in the lungs.
- Symptoms may include shortness of breath, collapsed lung, chest pain, cough, and/or fatigue. As many as 40 percent of women with LAM have a benign kidney tumor called angiomyolipoma.
- LAM does not usually appear on an x-ray. A high-resolution CT scan of the chest, and often the abdominal area, is required for accurate diagnosis.
- Lung capacity progressively declines, sometimes resulting in the need for supplemental oxygen.
- Women often go undiagnosed for years, and are frequently misdiagnosed with asthma, bronchitis, or emphysema.

Source: The LAM Foundation—
www.thelamfoundation.org

collapses. Other times, checkups with my doctors or periodic tests catch problems, so it's important to regularly seek medical care even if I'm feeling good.

I've had a progression that has been slower than some and faster than others—a blessing and curse with no predictable course or control.

It's been hard for me to accept. Most people in their 30s don't have to deal with the gravity of issues that results from this "double whammy." It's cheated me out of some very important things.

Yet, I have reason to hope. Understanding and advances in both diseases has come leaps and bounds, and there are drug trials that seem promising. The puzzle pieces for my diseases are coming together.

That keeps me hopeful that one day I'll have the chance to win the match. I have won a few rounds since 2009. I started a medication that has stopped the roller coaster of constant hospitalizations and checkups, and it allows me to focus on my job and hobbies.

Even if I lose in the end, I can rest assured knowing that I did not go down without a fight, that I gave it my best effort, and that by sharing my story I might have inspired another brave soul to stay in the fight and win.

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