

My name is Danielle Benich, and I am currently a stay-at-home mom who happens to have a rare progressive lung disease. I was initially diagnosed with lymphangioleiomyomatosis or LAM for short in December 2008 from a CAT scan of my lungs.

What you would need to know about LAM:

- “Lymphangioleiomyomatosis, better known as LAM, is a progressive, frequently fatal lung disease. It affects women almost exclusively, usually striking during the prime of their life.
- A person with LAM typically experiences symptoms such as shortness of breath, chest pain, chronic cough, fatigue and/or one or more lung collapses.
- LAM is characterized by an unusual type of smooth muscle cell that invades all tissues of the lungs and grows uncontrollably. Over time, the LAM cells obstruct the flow of air, preventing the lungs from providing oxygen to the rest of the body and making breathing a daily battle.
- In the early stages of LAM, most patients can go about their daily activities, but as the disease progresses, patients may have very limited mobility, require oxygen, and as a last resort lung transplantation.”<sup>1</sup>
- There is no cure and no treatment has been proven to be effective.<sup>2</sup>

Frustratingly enough, it took several years for me to receive the correct diagnosis. I had to switch physicians more than once, and I had to deal with doctors who belittled and discredited my symptoms. I eventually found a local pulmonologist who strongly recommended that I take a pulmonary rehab course. I wasn't all that excited about it to say the least. I'm a pretty introverted person for the most part – and I've never been comfortable exercising outside the home.

I finally agreed to go just long enough to learn how to utilize the oxygen properly so I could exercise again. My age made me feel very awkward, being the only person in their thirties there, meant I stood out way too much for my comfort level. Also the program was designed more for those old enough to be grandparents rather than a parent of young children, and it was difficult trying to adjust the format to suit my age and my particular illness. It was a rather frustrating experience all around, while I had to carefully express my concerns with the exercises and slow progression of the rehab course in regards to my condition. For someone much older with more of a standard COPD condition, it was great and just what was needed. For me, not so much.

I also found the scheduling of the rehab (right in the middle of the day), very inconvenient and not conducive. Who wants to get up, get all ready – including make-up and hair – take your kids to school, run your needed errands and whatever, then in the middle of the day – go work out? Then go through the entire process of getting ready again for the remainder of your day, picking up your kids and taking them to whatever practice or event happened to be going on that evening. I understand that especially for initial visits where a lot of information and explanations are given for the rehab, mid-day appointments are necessary. But for the actual rehab itself, I felt that a little more flexibility should have been available – especially early morning times.

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<sup>1</sup> The LAM Foundation “Family and Friends” <<http://www.thelamfoundation.org/family-and-friends.html>>

<sup>2</sup> The LAM Foundation “...but you look so healthy!” brochure

However, thankfully the ladies conducting the rehab course were willing to listen, learn and adapt the course to help me determine how I can best exercise with LAM and my unique needs. While I was never comfortable at rehab, I was able to finish the entire program and learn a lot about oxygen and my needs with LAM in regards to exercising. Most importantly, I felt better physically as well as emotionally with the ability to exercise on a regular basis again.

Being diagnosed with LAM has forced me to put my health first and foremost. With the supplemental oxygen, I exercise almost daily – thanks to the knowledge that I gained from pulmonary rehab. I have also become more knowledgeable about food and nutrition, and I am working towards achieving a healthy weight for myself. So far, I've lost 20 pounds and dropped three sizes. I think the combination of exercising and watching what I eat has improved my breathing and helped me with my stamina. My goal is to keep myself as healthy as I possibly can within my limitations.

My faith is that the research into LAM, lung transplants and other pulmonary topics continue to progress and give me and other patients something to hope for – your research into these very topics has had and will continue to have a real and tangible significance which can quite literally change our lives. The American Thoracic Society, the LAM Foundation, and all the researchers and scientists who devote their time and energy to learning more about pulmonary diseases, reassuring and educating patients who find themselves diagnosed with pulmonary diseases, and pursuing new and innovative treatments and cures for diseases give us our “breath of hope”. Thank you for all that you do.