

My name is Danielle Benich, and I am currently a stay-at-home mom. I am happily married to my best friend now for almost 15 years, and I have been blessed with two children – a girl and a boy. I was initially diagnosed with lymphangioleiomyomatosis or LAM for short right before the holidays in December 2008 from a CAT scan of my lungs. *“Merry Christmas to me!”* The asthma/allergy doctor that broke the news to me, told me to go see a specialist after the holidays and not look online and read anything about LAM until then.

Like I wasn't going to look online and see what this illness that I couldn't even pronounce was! Of course, a lot of the information found online was pretty horrid:

- A rare, fatal lung disease generally occurring in woman of childbearing age
- No treatments or cure
- With a grim prognosis of a life expectancy of 5 to 10 years being the worst

In 10 years time, my daughter would have been only 19 and my little boy, 15. Even worse – in 5 short years, my daughter would have only been 14, and my little boy, 10. I kept doing this math over and over in my head. It was completely unacceptable to me. I did not want to even consider that my children may have to grow up without their mother. Then to make matters even more dreadful, I wasn't sure when that 5 to 10 year life expectancy started – since I could look back several years and see when symptoms originated with my illness. So I kept incessantly doing that evil math in my head realizing that I wouldn't live to see my children grow up. My husband and I decided that waiting until the holidays was over would not work for us. Both of us were too upset, and we wanted answers now.

We were able to schedule an appointment with a pulmonary specialist in the Chicagoland area, which was within driving distance for us, before the holidays. I think a little part of me was really hoping that the person who read my CAT scan in our small town made a mistake, that there was something else going on with my shortness of breath. That little piece of hope I was holding on to was shattered as they pretty much confirmed the diagnosis. When alarms are going off with medical equipment while you are doing a simple walking test upstairs, and the personnel is telling you to stop and rest, please don't continue – I knew then something was drastically wrong. Since it was so rare, they had only seen a few other individuals with LAM and didn't know all that much about it. Basically all they could tell me was that I would need supplemental oxygen probably starting now and when my lungs got bad enough – I would need a lung transplant. It was devastating. I have always taken care of myself – I never smoked, never drank, I exercised relatively often and was careful what I ate. I felt betrayed by my body.

We quickly made an appointment with a specialist on LAM in Ohio, Dr. Frank McCormack -- the earliest we could get in was mid-January. We also contacted the LAM Foundation online, asking for more information, since our appointment was a few weeks away. I was pretty depressed. I had been told to stop exercising, I was gaining weight and my breathing seemed to be getting worse – and I just felt as if I was sliding into this black hole of despair. Thankfully, the LAM Foundation contacted us back pretty much immediately, giving us more up-to-date knowledge on LAM, sending us an informational packet in the mail, and basically giving us back some hope. We even received a phone call from the LAM Foundation's founder, Sue Byrnes, who was just calling to let us know that we weren't alone in this

journey. The essential information to me was that the 5 to 10 year life expectancy was mainly outdated, and that there were actually clinical trials started focused on finding treatments for LAM.

Somehow, during this nightmare which just wouldn't seem to end, the rest of your life goes on like normal. My kids still have to go to school, do homework, go to soccer practices, celebrate holidays and special events – while I still have the never-ending laundry, dishes, cooking, and all the other normal household chores that go along with having a family of four. It's a really hard balance trying to not upset the kids, keeping their life as normal as possible, while I felt that our life had been completely thrown into turmoil.

Before we even made it into the specialist, we received our packet in the mail from the LAM Foundation. It had a plethora of information in there, including two booklets – one which thoroughly explained LAM and the other was filled with stories of woman who had LAM. I had a really hard time going through all the information. I had to take it in little bits and pieces, pretty much constantly crying. But it gave us a solid foundation into what LAM was, so by the time we met with the LAM specialist, we had a good handle on what LAM was all about. The specialist did give us more information about having a definitive diagnosis (and the need to have one to participate in trials), the importance of how to handle a pneumothorax (especially considering the possibility of needing a lung transplant down the line), and stressed that LAM can vary significantly on how it progresses with each individual. I was advised to find a local pulmonologist to work with, monitoring and helping me with my chronic illness.

What you would need to know about LAM:

- “Lymphangiomyomatosis, 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. My last asthma/allergy doctor, while his method of informing me of LAM left a little to be desired, at least listened to me and acted on the fact that my symptoms weren't getting any better. Without his follow up tests on my heart and lung functions, I could still be mistreated for asthma even today.

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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

I did find a local pulmonologist who I am currently working with – he strongly recommended that I take a pulmonary rehab course at our local hospital. I wasn't all that excited about it to say the least. I'm a pretty introverted person for the most part – and I was quite resistant to the idea. In the end, I agreed to go just long enough to learn how to utilize the oxygen properly so I could exercise at home. 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 particular illness. 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. In the end, 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.

I am currently on supplemental oxygen mainly when I sleep (3L) and exercise (between 6L and 9L depending on if I'm lifting weights or on the treadmill). If I exert myself too much, such as too many stairs or too much walking, I need it at other times – but I'm not all that excited about wearing oxygen in public, so I severely limit any exertions that require oxygen outside the home. My FEV1 percentages in 2008 were in the 60% range, then in 2009 my FEV1 percentages were in the 45-55% range, and I haven't been tested for 2010 yet to see what, if any, progression LAM has continued to have with my breathing capabilities.

To look at me, I appear very healthy. I know many people probably have no idea that I have a chronic lung disease. But it has changed everything, not only for me, but also for my family. While we live close enough to the children's school to walk, it's simply too far for me anymore. I used to volunteer for most of the field trips, but many of them are too physically demanding with my illness now. My daughter is in travel soccer -- needing oxygen to sleep means part of our precious storage place in the car is filled up with my oxygen concentrator, and some of the fields are simply too far away for me to walk to (let alone help carry anything).

Many activities that parents tend to take for granted that they can spend with their children, such as walking trails, riding bikes, or playing sports are simply out of my reach now. Daily activities such as housework can be exhausting at times. Many times I've run out of "steam" by the afternoon even though my day is far from over with homework and soccer practices still to come, at the very least.

Financially, things are tough. We made the decision as a family that I would stay home with the children when they were young and find a job when they were both in school full-time. Now we're struggling to find a part-time job that I think I can physically handle – that overlaps the kids school schedule as much as possible, because if we end up having to pay childcare – we're not coming out ahead. I am still a Close To My Heart consultant, but after my diagnosis I had to stop my workshops and clubs. I needed to find areas of my life where I could cut back.

While I loved teaching how to scrapbook and stamp, and still do it personally, the commitment of monthly classes and workshops was getting to be too much for me to handle anymore. While my family may understand that I'm simply exhausted today and can't follow through with our original plans for the evening, I felt that my customers would have more of a problem with a lack of consistent dates. While I don't miss the late nights preparing marketing materials, designing projects and putting together packets – I do miss the camaraderie of the classes and teaching and visiting with other people who love the same craft I do. Now I simply struggle with finding pockets of time to do my personal craft projects, as normally I did all that after I put my children to bed, and staying up late really isn't an option anymore.

I worry a lot. There isn't any way that I can get through an entire day without thinking about LAM and its effect on me and my family. At the very least, when I need oxygen to sleep, I am quickly reminded every evening – even if I've somehow managed to forget for a little bit during the day. I worry about how fast LAM will progress in me. I worry about how long I'll be able to maintain the relatively "normal" lifestyle I have now. I worry about needing oxygen 24/7 and dealing with all the issues that come along with it. I worry about becoming a burden to my family, being unable to do all those daily tasks of a mother and wife. I can hardly think about the possibility of a lung transplant. I find the entire thought of the prospect of needing such a drastic medical procedure completely surreal and utterly terrifying.

Being diagnosed with LAM has forced me to put my health first and foremost. With the supplemental oxygen, I exercise almost daily. I have become more knowledgeable about food and nutrition, and I am watching what I eat as well as what my family eats. Even though I would have only considered myself slightly overweight, 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.

Even with the limits that my illness has placed on my lifestyle, I still feel very blessed. I have a supportive husband who always steps up to the plate when I need him. I have been able to graduate from high school and college, get married and have two children before my diagnosis. I have extended family and friends who understand and support our family when needed. Many other LAM patients we've come to know aren't so lucky – their spouses have left them due to the pressures of the illness, their family or friends aren't understanding of their health limitations, many of them are debating whether or not to have children as LAM may worsen with pregnancy, and finally some of them are just so young they haven't even started "their adult life" yet before being diagnosed.

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.