Patricia Ortiz

LYMPHANGIOLEIOMYOMATOSIS (LAM)

Patricia Ortiz was a patient speaker at the ATS 2018 International Conference in San Diego, California.

It was a devastating day when I was diagnosed with Lymphangioleiomyomatosis (LAM). LAM is a rare progressive lung disease leading to the cystic destruction of the lungs over time. Being an athlete for most of my life, none of my physicians had ever suspected anything was seriously wrong with me, even when I started presenting with respiratory symptoms and unexplainable chest pains back in 2009. Other symptoms that I now know are related to LAM started as far back as 2005.

Right before I was diagnosed in January of 2012, I was at the peak of my athletic capacity. I had received my category upgrade that allowed me to compete alongside professional athletes and had just returned from the National Championships for road cycling when suddenly everything changed. On December 29, 2011 I was admitted to the hospital with a large lung collapse. A lung biopsy revealed that I had LAM. My once bright future as an elite athlete seemed over. I thought I would never be able to compete again, and soon found myself not even strong enough for most recreational rides in my area.

Looking healthy and being athletic is a true gift but when it comes to having a rare disease, it can lead to missing important early signs. Some oxygen testing such as the "six-minute-walk test" were not as applicable to me, as I might not have de-saturated during a walk test but would have benefitted from oxygen therapy at a higher level of activity. My journey of

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misdiagnoses included everything from asthma to bronchitis to a possible anxiety attack. After that, I truly thought that the strange symptoms I was experiencing were all in my head.

Being under the care of the multidisciplinary team at USCD was a blessing. I think what made the difference for me was that the pulmonologist who correctly diagnosed me looked beyond my otherwise healthy appearance and spent a lot of time asking me a million questions.

Upon my diagnosis, I became very active in the LAM community. The LAM Foundation and scientific community provided me with a wealth of information, and I had the opportunity to connect with the NIH, enrolling in one of their natural history studies of LAM. I have also become an advocate for improved oxygen delivery technology and accessibility. The oxygen needs of LAM patients appears to be higher than the majority of oxygen users, yet oxygen delivery technology severely lags behind the need, so I'm passionate about changing that.

The work done at the NIH gives me hope. I realize that a cure for LAM may not be found in our lifetime, but I do continue to hope that in the future there are more answers for the next generation. ■

Lymphangioleiomyomatosis (LAM)

Lymphangioleiomyomatosis (LAM) is a progressive cystic lung disease typically manifesting in women of reproductive age. LAM can be either sporadic or associated with tuberous sclerosis complex (TSC). LAM involves smooth muscle proliferation that contributes to parenchymal cysts formation in the lungs. While LAM is considered an interstitial lung disease, clinically, it is essentially a cystic lung disease and shares significant physiological features of emphysema including bilateral multiple cysts and airflow obstruction.

- Symptoms may include shortness of breath, collapsed lung, chest pain, cough, fatigue.
- Women with LAM may be misdiagnosed with asthma, emphysema, or bronchitis.
- Median survival in patients with LAM has varied from 10 to 30 years.

Learn more: ATS Public Advisory Roundtable member The LAM Foundation. ***www.thelamfoundation.org***.