

Madeline Williams

LYMPHANGIOLEIOMYOMATOSIS (LAM)



In 2005, when I was 29, I was diagnosed with a rare lung disease called pulmonary lymphangioleiomyomatosis (LAM). I started out with very few symptoms. I had been a runner for many years, and in 2008 I started having continuous lung collapses. After several unsuccessful surgeries, it became painfully obvious that I would need to get on the transplant list in the future. On oxygen for 18 months, I waited to be considered “bad enough” to be listed for a transplant. During this time, I was rushed to an ER in Arkansas for tachycardia then transported to Dallas by plane to begin the process of getting ready for a transplant.

At this time, a family friend offered his new home in Dallas while we waited for the call. In March 2009 I collapsed there and was rushed to UT Southwestern to prep for transplant. My heart gave out twice during the surgery but the dedicated staff hand-pumped my heart. After a long two-month recovery in the hospital, I was released.

Madeline Williams was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

Lymphangi leiomyomatosis (LAM)

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In the 10 years since my transplant I have traveled to Ireland, parasailed in upstate New York, and visited Disney World and New Orleans, among other places. I believe my overall success can be attributed to my commitment not to ever give up, and to enjoy life to the fullest. As long as I can still grab a breath, I will continue to fight. ■

LAM is a rare lung disease that mainly affects women, usually during their childbearing years. LAM occurs in 3-8 women per million in the general population. 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.

Symptoms of LAM are similar to other lung diseases. Sometimes patients can be misdiagnosed with asthma, bronchitis, or emphysema. These symptoms include:

- Shortness of breath.
- Fatigue.
- Lung collapse, also known as a pneumothorax.
- Chest pain.
- Cough.
- Coughing up small amounts blood.

*Learn more: [ATS Public Advisory Roundtable member The LAM Foundation.](#)
www.thelamfoundation.org.*