

10 Facts About Lymphangiomyomatosis (LAM)

- Symptoms may include shortness of breath, collapsed lung, chest pain, cough, or fatigue.
- Up to 50% of women with LAM have a benign kidney tumor called angiomyolipoma.
- LAM usually does not appear on an x-ray. A high-resolution CT scan of the chest, and often the abdominal area, is required for accurate diagnosis.
- LAM results in progressive destruction of healthy lung tissue caused by cyst formation and abnormal growth of smooth muscle cells, not usually found in the lungs.
- Lung capacity progressively declines, resulting in the need for oxygen therapy.
- Women often go undiagnosed for years, and are frequently misdiagnosed with asthma, bronchitis, or emphysema.
- The discovery of a genetic link between LAM and tuberous sclerosis (TS) leads scientists to estimate that more than 250,000 women worldwide are unaware they have LAM.
- Since LAM occurs almost exclusively in women, the disease is thought to be hormonally-related.
- Many doctors think pregnancy accelerates the disease.
- There is no cure and no treatment that has proven to be effective, but treatment trials are underway.

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