



## INFORMATION TO GIVE TO A POTENTIAL PELVIC FLOOR THERAPIST

Hi, I have been diagnosed with LAM and am seeking pelvic floor physical therapy. Since LAM is a very rare disease, I wanted to share some information to help. The following information is from [www.thelamfoundation.org](http://www.thelamfoundation.org)

### What is LAM?

**Lymphangiomyomatosis** (lim-FAN-je-o-LI-o-MI-o-ma-TO-sis), or LAM, is a rare lung disease that affects women almost exclusively. LAM is characterized by an abnormal growth of smooth muscle cells, especially in the lungs, lymphatic system, and kidneys. Abnormal growth of these cells can lead to loss of lung function, accumulation of lymph rich fluid in the chest and abdomen, and growth of benign tumors in the kidneys.

**The LAM cells cause blockage of the small airways and damage the lung tissue, reducing airflow and oxygen absorption in the blood.**

### Symptoms of LAM

- Dyspnea during and after exertion
- SOB
- Fatigue
- Spontaneous and recurrent pneumothorax
- Cough / Wheezing
- Chest pain
- Abdominal bloating
- Kidney angiomyolipoma
- Lymphatic complications - abundance of chylous fluid

### Treatment options of LAM

- Sirolimus medication to stabilize or slow the rate of decline
- Bronchodilators
- Supplemental oxygen
- Pleurodesis, pleurectomy
- Pulmonary rehab
- Thoracoscopy, thoracotomy
- Lung transplant

### **LAM characteristics that could potentially affect the pelvic floor (the following is extrapolated by Miles Pelvic Therapy)**

While it hasn't formally been researched, the following is extrapolated from what we know about pelvic floor dysfunction and limitations in lung capacity, diaphragm function, and rib cage mobility.

- SUI – University of Washington survey reports 72% of LAM patients are reporting SUI
- Potential increased tension in pelvic floor muscles due to poor diaphragm function or pelvic floor muscle weakness due to decreased overall activity, chronic hypoxia
- Potential constipation (decreased diaphragm mobility) or diarrhea (side effect of sirolimus)
- Potential abdominal weakness and decreased trunk stability
- Potential back pain, rib pain
- Potential dyspareunia

### **General Thoughts**

- Monitor oxygen saturation during exercise sessions
- Monitor HR during exercise sessions
- Maintain strict precautions to minimize exposure to germs and reduce the risk of infection
- LAM is fueled by estrogen, but the prevailing thought is that vaginal estrogen is considered safe, and systemic estrogen is typically not recommended, but always consult with the LAM team
- Sirolimus side effects: stomach pain, headache, constipation, diarrhea, nausea, joint pain, hyperlipidemia (Medlineplus.gov)



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