



The LAM Foundation Media Kit

Mission

The LAM Foundation urgently seeks safe and effective treatments, and ultimately a cure, for lymphangioleiomyomatosis (LAM) through advocacy and the funding of promising research. We are dedicated to serving the scientific, medical, and patient communities by offering information, resources, and a worldwide network of hope and support.

What is LAM

LAM is a rare, progressive lung disease that primarily affects women and causes pulmonary cyst formation, small airway obstruction, and eventually, respiratory failure. LAM's first treatment, the drug Rapamune (generic name: sirolimus), was approved in 2015.

The LAM Foundation

Since 1995, The LAM Foundation has been the global leader in the fight against LAM. The New England Journal of Medicine cites The LAM Foundation as "a model for patient advocacy." The National Heart, Lung, and Blood Institute called The LAM Foundation "a model for voluntary health agencies."

Services and Resources

- **Patient and Family Support** through education, advocacy, and a safe place to learn from others who live with LAM.
- **Fund Promising Research** by directing funds to LAM scientists and facilitating collaboration and access to resources.
- **Improve Access** to Expert Care by supporting a global network of LAM clinics and clinical trials.
- **Produce Educational Events and Conferences** that bring patients, families, clinicians, and scientists together.
- **Raise Money** and assist the LAM community with local fundraising events and programs.

Key accomplishments:

- First FDA-approved treatment for LAM – Rapamune (sirolimus), May 2015; Approved in 41 countries and widely prescribed globally.
- Patient Database of 3,750+ patients; Estimated 10,000 registered patients in Worldwide LAM Patient Coalition.
- \$33.5 million raised – more than \$18.5 million dedicated to research activities, additional investments in education, patient support, and awareness activities.
- 70+ member Global LAM Clinical & Research Network.
- ATS/JRS LAM Clinical Practice Guidelines.
- 23 LAM Research Conferences & LAMposiums.
- 26-year LAM research protocol at the National Institutes of Health (NIH).
- 19 Members of the Worldwide Patient Coalition.
- 28 regionally based LAM Liaisons that offer support and resources for LAM families. All are women living with LAM who volunteer their time.



Research funded by The LAM Foundation has also proven central to understanding other, more common diseases such as cancer, diabetes, and obesity.

The LAM Foundation's work is far from complete. There is still work to be done including:

- Maximizing the effectiveness of the current treatment, sirolimus.
- Supporting clinical trials.
- Facilitating research to improve the quality of life for women living with LAM.
- Reducing the time to an accurate diagnosis: an untold number of women with LAM remain misdiagnosed or undiagnosed.
- Serving as a model for other rare disease organizations and sharing knowledge to propel treatments and cures for rare and common diseases.

More on LAM

A LAM patient's lungs are invaded by mutant smooth muscle cells, which dissolve healthy lung tissue and replace it with innumerable air-filled holes or cysts. Debate is ongoing about the links between LAM and cancer.

LAM is often misdiagnosed. Early symptoms may resemble asthma, emphysema, or bronchitis. Chest X-rays may look normal. The most useful imaging test for diagnosing LAM is a high-resolution CT-Scan, which is expensive, and physicians usually do not order it early, especially physicians unfamiliar with LAM.

A LAM diagnosis once meant certain lung failure leading to a lung transplant or death. Now, LAM patients' outlook often centers on the word "hope." In great part, this is due to The LAM Foundation's strategy of "relentless collaboration" with researchers, clinicians, patients, and government health agencies around the world.

More on Rare Diseases

There are 7,000+ known rare (or orphan) diseases. A rare disease is one that affects a small percentage of the population. In the U.S., a rare or orphan disease is a disease or condition that affects less than 200,000 people. Collectively, rare diseases are a major problem—one in 10 Americans is affected by a rare disease, with many of them being children.

Conservative estimates suggest that there are approximately 8,000 – 12,000 patients with sporadic LAM and 80,000 – 160,000 patients with TSC-LAM worldwide. Although TSC-LAM appears to be more common, more than 80% of patients with LAM in pulmonary clinics, registries, and trials have sporadic LAM. Of the 7,000 rare diseases, LAM is one of only 500 with a treatment, but still no cure.

Progress to find treatments and cures for rare diseases is typically slow because populations are small, research is often ignored and costs to develop treatments and cures are unlikely to be recovered.

Investment in LAM and rare disease research is vital, not only for patients but also because such research contributes to discoveries in other diseases such as cancer and diabetes.



Resources

For more information about The LAM Foundation, or to arrange interviews, contact:

info@thelamfoundation.org or 513-777-6889.

[The Patient Voice Video](#)– This short video provides an excellent summary through the eyes of patients.

[The LAM Foundation](#) – The LAM Foundation’s Website