About The LAM Foundation – The Soundbite Ready Answer

The LAM Foundation works to urgently find better treatments and a cure for LAM, a rare lung disease that mostly affects women. It brings together scientists, doctors, and patients to share knowledge, support each other, and push research forward. Thanks to this teamwork, there is now an FDA-approved treatment for LAM and I hope for even more breakthroughs.

About The LAM Foundation – The Conversation Ready Answer

The LAM Foundation is leading the fight against a rare lung disease called LAM (lymphangioleiomyomatosis). LAM mostly affects women and can cause serious breathing problems. The Foundation works to find better treatments — and one day, a cure.

Since it began in 1995, The LAM Foundation has grown into a trusted organization that helps scientists, doctors, and patients all around the world. It shares up-to-date information, supports patients, and brings experts together to push research forward.

While LAM is rare, it affects women of all races in over 60 countries. New studies suggest it may be more common than we once thought. That's why awareness and research are more important than ever.

Here are a few highlights of what The LAM Foundation has done:

- Helped create the first FDA-approved treatment for LAM: sirolimus.
- Built a global network of 74+ LAM Clinics to give patients expert care.
- Funded more than $19 million in research, helping to unlock over $90 million more in federal support.
- Created a Circle of Hope program for women going through lung transplants.
- Collected tissue samples and built databases to help researchers learn more about LAM.
- Advocated for the needs of the LAM community including the SOAR and protections for rare disease research funding.

The LAM Foundation also brings people together biennially for LAMposium — a special meeting where patients, scientists, clinicians, and families connect and learn from each other.

Together, we're making progress — but there's still more to do. With your help, we can keep moving forward.

About The LAM Foundation – The Complete Answer

The LAM Foundation is the global leader in the fight against LAM (lymphangioleiomyomatosis), a rare lung disease that strikes young women, often in the prime of their lives. A 501(c)(3) non-profit, the Foundation's mission is: to urgently seek safe and effective treatments, and ultimately a cure, for 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.

The largest study to date of LAM patients estimates that for every million women, three to seven will have LAM. However, a 2023 study of four European countries suggests a prevalence of **at least 21 cases per million women.** All races are affected, and cases have been identified in more than sixty countries.

Founded in 1995 in Cincinnati, Ohio, as a grassroots effort, The LAM Foundation has evolved into an organization that is described by the National Heart, Lung and Blood Institute (NHLBI) as "a model for voluntary health agencies." The Foundation has provided a vehicle to organize and focus the LAM community to facilitate patient support, informed clinical care, scientific interchange, and research.

Highlights of The LAM Foundation's accomplishments include:

- A patient database of 4,000+ women with LAM, with an estimated 10,000 registered patients globally. Additionally, we helped create the Worldwide LAM Patient Coalition to support LAM patients around the world.
- Funding clinical trials leading to the first FDA-approved treatment for LAM, sirolimus – approved in 41 countries and widely prescribed globally.
- A network of 74+ global clinics (39 in the U.S. and 35 overseas), each led by a dedicated LAM Clinic Director, to facilitate high quality, multidisciplinary care of LAM patients and provide a platform for research.
- More than $19 million of the nearly $37 million raised to date has been committed to LAM research, including grants awarded for more than 168 projects to unique investigators to study the basic mechanisms of disease in LAM, as well as clinical trial support.
- **The LAM Foundation's initial investment of $12 million in scientific grants has led to an additional $90 million in federal funding for LAM research.**
- Creating the ATS/IRS LAM Clinical Practice Guidelines to facilitate early diagnosis and improve patient care.
- Providing resources to LAM patients considering lung transplant through the Circle of Hope Transplant Support Program, supporting their transplant journey while also assuring that rare and valuable tissue is made available to LAM researchers.
- An NHLBI-funded tissue bank at the National Disease Research Interchange (NDRI), including a system for tissue acquisition and distribution of LAM bio samples for research purposes.
- Since 1995, an NHLBI LAM research protocol has enrolled more than 800 LAM patients.

- 23 International LAM Research Conferences & LAMposiums since 1999 – meetings which have strengthened and focused the efforts of the scientific community to understand the disease.

Looking forward, The LAM Foundation's work is far from complete, and much remains to be done. Future research priorities include:

- Maximizing the effectiveness of the current treatment, sirolimus (related to optimal dosage and long-term effectiveness), while continuing the search for a cure.
- Determining the mechanisms of immune evasion in LAM.
- Understanding the role of female hormones in disease pathogenesis.
- Developing novel diagnostic, prognostic, and predictive biomarkers.
- Improving the quality of life for women with LAM who are living longer – including reproductive health, pregnancy, fatigue, and nutrition.
- Finding and quickly diagnosing the untold number of women with LAM who currently remain undiagnosed in the U.S. and globally.
- Maximizing opportunities for The LAM Foundation to serve as a model for other rare disease organizations, and to share knowledge to propel treatments and cures in rare and common diseases.

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