THE LAM FOUNDATION

A BREATH OF HOPE

About The LAM Foundation

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 17-member 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 73 global clinics (39 in the U.S. and 34 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 $18.7 million of the nearly $35 million raised to date has been committed to LAM research, including grants awarded for more than 157 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 diagnosed 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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