

10 FACTS ABOUT LYMPHANGIOLEIOMYOMATOSIS (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 tumour 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 that they have LAM
- Since LAM occurs almost exclusively in women, the disease is thought to be hormone-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

LAM ACTION



Please Support LAM Action

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Donations should be sent to Jan Johnson, LAM Action, at the above address.
Cheques should be made payable to LAM Action.
Donations can also be made online via the JustGiving website
www.justgiving.com/lamaction/donate

LAM Action is a registered charity, no.1096637

PLEASE SUPPORT LAM ACTION

Working for patients with
Lymphangioleiomyomatosis

About LAM Action

LAM Action is the UK charity for patients and families with lymphangioleiomyomatosis (LAM) and doctors caring for patients with LAM.

It has two primary aims:

- To provide support and information for LAM patients and their families
- To educate health professionals about LAM and advance research into LAM

A third objective of LAM Action is to raise money to fund its primary activities.

Medically, LAM Action is supported by the respiratory group in Nottingham. Scientists there are carrying out research into LAM, led by Dr Simon Johnson.

LAM ACTION

Patient Support

A primary aim of LAM Action is to provide support, information and encouragement to LAM patients, their families and health professionals.

We do this in a number of ways

- **Website** Our comprehensive website is www.lamaction.org
- **Email support group** We have established an active patient chat-line, LAMline, for discussions and support via email
- **Patient-to-patient contact** We also have an informal network of patients willing to talk and provide support to others; this can be of particular help to newly diagnosed patients
- **Newsletter** LAMPost is generally published quarterly
- **Annual Meeting** Once a year, we hold a day-long meeting in Nottingham for patients and their families
- **Fact-sheet** We have produced a fact-sheet on LAM for doctors and patients
- **PR** We employ PR consultants to raise awareness of LAM

- **Links with other organisations** We maintain strong links with the medical profession and with other organisations and groups around the world interested in LAM, covering patient support, treatment best practice and medical research

If you are interested in any of the above services, please get in touch with the LAM Action coordinator, Jan Johnson, in the first instance. She can be contacted through LAM Action (details overleaf).

Research

Currently there is no cure for LAM and no effective treatment. Therefore, advancing research into LAM is a very important part of LAM Action's work. There are two aspects of the research:

Basic research to find the cause of LAM

The charity has established and funded a basic research programme in Nottingham. The research is currently focused on the role of proteins, which are abnormal in LAM, to investigate why LAM cells grow in the lungs and the mechanism of lung damage by LAM cells.

Clinical studies of treatment in patients

There are now several promising therapeutic approaches for LAM and these require clinical trials in patients. In the UK, two trials involving separate drugs are currently underway. We are now into the second year of a two year trial to test the efficacy and safety of the drug rapamycin in patients with LAM and tuberous sclerosis. This trial is an important milestone for the charity and LAM patients as it marks the first time in the UK that a drug trial has been carried out for LAM patients. It complements and augments similar work being done in the United States.

More recently, the scientific team in Nottingham has gained approval and funding for a further LAM treatment study to determine whether the commonly used antibiotic doxycycline slows the progression of LAM. Although the team was awarded a grant to cover some of the costs of this trial, LAM Action is also making a significant contribution.

Such research also has other benefits. We need to appoint clinical researchers to run the trials, but we hope that they will also have time to help with other aspects of LAM research and perhaps develop a long term interest in LAM.