

10 FACTS ABOUT LYMPHANGIOLEIOMYOMATOSIS (LAM)

- LAM mainly affects the lungs, where it results in progressive destruction of healthy lung tissue
- The rate of progression varies considerably amongst those with LAM
- Symptoms may include shortness of breath, collapsed lung, chest pain, cough or fatigue
- Up to half of women with LAM have a benign kidney tumour called an 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
- Lung capacity progressively declines, sometimes resulting in the need for supplemental oxygen
- Women often go undiagnosed for years, and are frequently misdiagnosed with asthma, bronchitis or emphysema
- Since LAM occurs almost exclusively in women and generally occurs before the menopause, hormones such as oestrogen are thought to play a part in LAM
- Recent years have seen significant progress in the understanding and treatment of LAM, thanks to cooperation between those with LAM and the medical and scientific communities
- This has already led to one drug, rapamycin (sirolimus), being used for women with more severe LAM. But there is still an urgent need to fund research to find a safe and effective treatment for LAM and, ultimately, a cure

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Registered Charity 1167610 (England & Wales)

Support LAM Action

Donations should be sent to Jill Pateman at the address below. Cheques should be made payable to LAM Action.

Donations can also be made online via
Virgin Money Giving

<http://uk.virginmoneygiving.com/charities/lamaction>

or JustGiving

<http://www.justgiving.com/lamaction/donate>

Contact LAM Action

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About LAM Action

LAM Action is the UK charity for those with lymphangioleiomyomatosis (LAM), their families and doctors caring for them.

LAM is a rare multi-system disease, diagnosed mainly in women of childbearing age. It predominantly affects the lungs, where it causes excessive growth of smooth muscle cells which progressively destroy lung tissue and erode lung function. Although research is ongoing, currently there is no cure for LAM and effective treatment is limited. For some, lung transplantation is their only means of survival.

LAM Action has two primary aims:

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

LAM Action raises funds to drive its primary activities.

Medically, LAM Action has always been supported by the respiratory group in Nottingham. In 2011, the National Centre for LAM was established in Nottingham to provide clinical care for those with LAM and facilitate scientific research into the disease. LAM Action has close links with this centre.

Support

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

We do this in a number of ways:

- **Website:** Our comprehensive website is www.lamaction.org
- **Fact-sheet:** We have produced a factsheet on LAM for doctors and those with LAM
- **Newsletter:** We publish LAMpost 3 times a year
- **Annual Meeting:** Once a year, we hold a day-long meeting for people with LAM and their families
- **Email support group:** We have established an active chat-line, LAMline, for discussions and support via email for those with LAM, and we are also active on social media sites such as Facebook & Twitter
- **One-to-one contact:** We have a network of women willing to talk and provide support to others. In addition, we run Regional Support Groups who organise local, informal gatherings
- **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

If you are interested in any of the above services, please get in touch with the LAM Action coordinator, Jill Pateman. Her contact details are overleaf.

Research

There has been significant progress in understanding LAM in recent years, but there is still no cure for LAM and effective treatment is limited. 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

LAM Action established and funds a basic research programme in Nottingham. The current focus of the team's research is on understanding how LAM cells interact with other cells, and the mechanisms by which their interactions lead to lung destruction.

Clinical studies of treatment

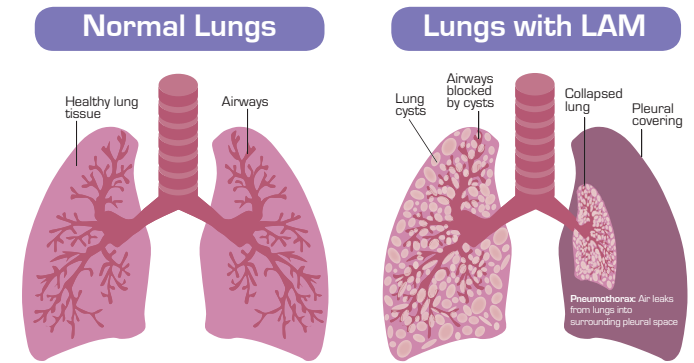
There are now several promising therapeutic approaches for LAM and these require clinical trials in those with LAM. In the UK, recent studies have focused on the drugs rapamycin and doxycycline.

In Nottingham, LAM Action jointly funded (with the British Lung Foundation) only the second randomised clinical trial of a possible treatment.

As a result of trials in the UK and USA of the drug rapamycin for the lung and renal manifestations of LAM, rapamycin was approved as a treatment for those with moderate to severe LAM in 2011. The trials had concluded that rapamycin stabilised the disease in those whose LAM is more advanced.

Progress in our understanding of the science behind LAM means there are many ideas for further drug treatment trials and biomarker studies. However, these trials and studies need funding and need those with LAM to participate; both present challenges in a rare disease such as

LAM. Therefore, it is crucial that we collaborate, share information and keep up-to-date with all developments around the world.



National Centre for LAM

The National Centre for LAM was established in Nottingham in April 2011 by Professor Simon Johnson. Although independent from LAM Action, those with LAM are clear beneficiaries of the centre and feedback from those who attend the centre has been very positive.

The centre:

- **provides those with LAM with specialist clinical care** on all aspects of LAM, either exclusively or in partnership with local providers
- **facilitates research into LAM**, including clinical trials of new therapies for LAM, biomarker studies and laboratory research into the disease.

Referrals to the National Centre for LAM should be made through a medical practitioner wherever possible.

Further information is available by emailing:

nuhnt.lamcentre@nhs.net

or visiting:

<https://www.nuh.nhs.uk/national-centre-for-lam>