



LAM ACTION

Supporting women with
Lymphangioliomyomatosis

Registered Charity no.1167610 (England & Wales)

www.lamaction.org

About LAM Action

“Learning from the experience of other women who have been living with LAM is helpful, encouraging and inspirational!”

What is LAM Action?

We are a UK registered charity

- We are run by volunteers, and all our income is from fundraising and donations
- We are independent from the NHS National Centre for LAM, but have close links to the medical and research staff there

What does LAM Action do?

We provide valuable support to women with LAM and their families

- One-to-one support from other women with LAM
- Private email and Facebook groups for women with LAM
- First line of contact telephone and email support offered by our coordinator, Jill Pateman
- LAMpost newsletter written by and for women with LAM
- Regional groups of women with LAM
- Annual meeting where women with LAM and their families meet, chat and learn from each other and from medical professionals

We raise money

- LAM Action has to date raised over £1.2 million, the vast majority of which has directly supported scientific research into LAM

We provide accurate information about LAM

- LAM Factsheet, pamphlet and other materials and online links
- Informative, up-to-date website www.lamaction.org
- Helped develop European Guidelines for treatment and management of LAM

We have built and maintain ties with medical professionals and other patient-led LAM groups around the world

We fund research into LAM

- Co-funded important global trials of sirolimus and doxycycline
- Over 25 research papers, guideline statements and scientific reviews on LAM produced by LAM Action-supported researchers, with LAM Action funding around half of these

Why should you become a member of LAM Action?

Benefits for you

- Gain access to the support we can offer women with LAM and their families
- Hear about the latest developments and progress in LAM treatment, management, and understanding
- Learn about opportunities to participate in trials, studies and other research

Benefits for the whole LAM community

- Help us show potential donors and researchers that we are reaching and supporting a significant number of the women in the UK with LAM. LAM is so rare, if we work together and share our experiences, we should ALL benefit

How do you join?

Simply complete a membership form and return it to us

- Download our membership form from www.lamaction.org or contact LAM Action's co-ordinator for more information
- Membership of LAM Action is FREE OF CHARGE

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