



LAM ACTION

Supporting women with
Lymphangi leiomyomatosis



Take a closer look at LAM Action

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
- LAMline private email group
- First line of contact telephone and email support offered by our coordinator
- LAMpost newsletter written by and for women with LAM
- Regional groups of women with LAM
- Annual meeting where women with LAM meet, chat and learn

We provide accurate information about LAM

- LAM Factsheet, tri-fold pamphlet and other materials
- Informative, up-to-date website www.lamaction.org
- Participation in development of European Guidelines for treatment 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 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

We raise money

- Nearly £900,000 raised in LAM Action's 13-year history
- Vast majority of funds support scientific research

What is LAM Action?

We are a UK registered charity

- We are run by volunteers
- We are not part of the NHS
- We are an independent organisation, separate from the National Centre for LAM

Why should you become a member of LAM Action?

Help us show donors and research funders that we are reaching and supporting a significant number of the women with LAM in the UK

- Approximately 240 women in the UK have LAM, fewer than half of whom are members of LAM Action. Yet many non-members receive our support and fundraise for us

We will be able to contact you directly about research that might affect you

- With a rare disease like LAM, having a "joined up" network of women who can participate in clinical trials and other research is hugely important

How do you join?

Sign up as a member and pay your membership fee

- Download our membership form from www.lamaction.com or contact LAM Action's co-ordinator for more information
- Your only obligation is to pay a membership fee of £20 per individual or £30 per household

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