LAM Action

Charity Number 1167610

Annual Report and Financial Statements

Year ended 31 December 2025

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Joanne (Jo) Pisani, Co-Chair Kelly Vance, Co-Chair (secretary through 2025) Sarah Sharples, Treasurer Clare Lyon, Secretary, (co-opted February 2025 and elected June 2025) Adam Davidson Harriet Davidson (resigned June 2025) Stephanie (Steph) Evans (co-opted October 2025) Tess Hill (resigned May 2025) Gillian Hollis Simon Johnson Ilona Leighton-Goodall (resigned June 2025) Leanne Lillywhite-Sutton, former chair (resigned March 2026) David Mercer Sally Merritt-Collins John Wood
Principal address	c/o Jill Pateman LAM Action PO Box 10933 Newark NG24 9QG
Registered Charity Number	1167610
Independent Examiner	Andrew J Davies FCA Kneeshaws Chartered Accountants Fourth Floor, St James House St James Row Burnley BB11 1DR

TRUSTEES' ANNUAL REPORT

The trustees of LAM Action (also referred to as the "Charity") hereby present their report and the Charity's financial statements for the year ending 31 December 2025.

OBJECTIVES AND ACTIVITIES

LAM Action was established to be the UK charity for those with lymphangioleiomyomatosis (also known as LAM), their families and the doctors caring for them.

LAM is a rare disease that occurs almost exclusively in women. Current estimates are that LAM affects approximately 10 to 20 in every million women. Excessive growth of cells in the lungs causes cysts and airways obstruction, leading to increasing breathlessness with episodes of lung collapse, coughing up blood and the development of fluid around the lung. LAM also affects the lymphatics and the kidneys, and around half of patients also have benign tumours in the kidneys. LAM is diagnosed mainly in women between the ages of 20 and 50 and usually progresses over time. In the absence of treatment, progression is usually slow with a gradual decline in lung function, increase in breathlessness and, for some women, the eventual need for supplemental oxygen. Some women require lung transplants and, tragically, some face end-stage disease. The rate of progression varies considerably between individuals and current research is trying to identify the reasons for this variation.

About 15 years ago, researchers discovered that the drug sirolimus (also known as rapamycin) can slow the decline in lung function in most women with LAM. Use of sirolimus has had a very positive impact on the progression of LAM for many women, and quality of life, severity of symptoms and survival rates have improved as a result. A few years ago, 90% of women were alive 10 years after being diagnosed with LAM, but with the increased use of sirolimus this figure has improved significantly and is likely to improve further.

However, sirolimus is not effective for all women with LAM, nor does it cure the disease. As a result, scientists continue to study other potential therapies and ultimately a cure for LAM.

The main objectives of LAM Action set out in its Constitution are:

1) to relieve persons diagnosed with or who are in the process of being diagnosed with lymphangioleiomyomatosis (LAM), their families and carers by the provision of support and information;

2) to advance research into LAM and disseminate the knowledge gained as a result of the research, including by supporting research which furthers understanding of LAM;

3) to increase awareness amongst health professionals about how LAM presents and where support for those diagnosed with the disease can be obtained, and to promulgate good clinical practice for the management of LAM amongst health professionals;

4) to share research, clinical and patient support experience with other medical, patient and research groups in the UK and overseas.

The only paid employee of LAM Action is the Administrator and Member Co-ordinator, Jill Pateman. All other activities are conducted entirely through the contribution of volunteers.

In 2025 LAM Action and our volunteers carried out person-to-person interactions on a 'virtual' (via Zoom/Microsoft Teams) and in-person basis, by telephone and email, via LAM Action's private email and social media groups and through our annual meeting held in Watford. LAM Action had 217 members at 31 December 2025, 69% of whom had LAM.

ACHIEVEMENTS AND PERFORMANCE

Advancing research and educating health professionals

Professor Simon Johnson, one of LAM Action's trustees, is a world-renowned expert in LAM. Amongst his accomplishments, he established and directs the National Centre for LAM in Nottingham ("LAM Centre") and co-leads the LifeArc Translational Centre for Rare Respiratory Diseases ("LifeArc RRD Centre"). Although the LAM Centre and the LifeArc RRD Centre are independent of LAM Action, the Charity frequently interacts with both and benefits greatly from Professor Johnson's expertise and stature as an expert in LAM.

In addition to providing comprehensive clinical care for women with LAM, the LAM Centre facilitates research work on LAM**.** For approximately 20 years, LAM Action has funded the salary of a senior member of the research team who works on LAM, Dr Debbie Clements. LAM Action continued to provide this financial support in 2025. Over the last year, Dr Clements continued to work primarily on research into extracellular matrix and collagen deposition in LAM, with the aim of determining whether collagen deposition is associated with LAM progression, therefore affecting lung function. Collagen deposition is a known target for drug research for other conditions, and may lead to opportunities to repurpose drugs for LAM, which could benefit patients with poor response to rapamycin and potentially move towards a cure for LAM. In 2025 Dr Clements authored two papers on this research, one of which was published in the *European Respiratory Journal* and the other in *Nature Communications*. Dr Clements also co-supervised two PhD students working on LAM research at Queens Medical Centre and helped prepare successful grant applications to the U.S. LAM Foundation and the Tuberous Sclerosis Association.

In light of Professor Johnson's role at the LAM Centre and his role as a trustee of LAM Action, the Charity's independent scientific advisor, Professor Stephen A Renshaw, evaluates ongoing research funded by LAM Action. In his report for 2025, Professor Renshaw noted that Dr Clements' research " is of a high quality, with both scientific merit and translational potential for patients with LAM" and, amongst other things, that the work focussing on four potential new drug targets for treating LAM shows "promise as adjunctive therapies to Rapamycin".

In addition to funding research, LAM Action solicits its members and otherwise offers patient input into various research initiatives. For example, LAM Action is one of five patient groups involved with the LifeArc RRD Centre, the aim of which is to become the foundation for fast-tracking rare respiratory disease therapies. LAM Action provided important input into the successful £9.4 million grant application for this project in 2023, and several LAM Action members played an active role in the project throughout 2025. LAM patients' continued involvement and engagement will be integral to the success of the project.

Treatment trials, studies and research into LAM are taking place around the world, and LAM Action keeps abreast of these developments through its links with the medical team at the LAM Centre, as well as other patient and scientific groups worldwide.

Support and information for those affected by LAM

The Charity works hard to provide information and emotional support to those with LAM and their families. Initiatives undertaken during 2025 by LAM Action's Executive Committee and other volunteers included:

- Continuing to provide one-to-one support to women with LAM, particularly to those newly diagnosed. Support is also provided to the family members of women with LAM or who have passed away from the disease.
- Continuing to provide regional peer-support groups, to help the LAM community interact with each other and discuss shared experiences and concerns. These groups met virtually or in person at least 14 times in 2025.

- Continuing to facilitate communication between women with LAM, primarily through the closed Facebook group LAM Talk UK, which had 235 members at 31 December 2025, and also through the lesser utilised private LAMline email support chat group.
- Maintaining LAM Action's website, one of the key aims of which is to direct those who are newly diagnosed with LAM to sources of information and support.
- Arranging the Charity's AGM and annual meeting for people with LAM and their families to hear about LAM research and meet people with the disease. In June 2025 44 people attended our in-person annual meeting held in Watford.
- Surveying our members and other users of our support services as part of our ongoing evaluation of our service offering.
- Continuing to produce our newsletter LAMPost three times a year, which includes a variety of stories, including personal profiles, medical news related to LAM, practical tips for living with the disease and fundraising news.
- Organising participation in the London Marathon and similar fundraising events.
- Continuing to update our internal systems to facilitate efficient record-keeping and member outreach and support.
- Maintaining close links with LAM patient groups internationally, particularly through the regular meetings of the Worldwide LAM Patient Coalition, in which information, experiences and best practices are shared.

FINANCIAL REVIEW

Revenues and Expenses for 2025

Total income of £157,609 was up in 2025 compared to £89,392 in 2024. This was due primarily to £79,218 in donations made specifically to fund research and to timing variances in Gift Aid receipts in 2025 compared to 2024. Fundraising was down by £28,267 in 2025 compared to 2024. This was due largely to the inclusion in 2024 of a fundraising event that raised £24,555 and to Ride London not being held in 2025.

Expenses of £115,683 were significantly higher in 2025 compared to £57,816 in 2024. This was due largely to timing variances in £43,274 of invoiced research salaries and to the charity's contribution of £20,000 toward research consumables. Our AGM expenses were £2,837 in 2025, compared to £3,201 in 2024. The charity has covered delegate rates, offered subsidies towards hotel rooms and incurred conference room and similar costs in connection with our in-person annual meetings for the past two years.

Reserves policy

Reserves stood at £322,524 at 31 December 2025. The trustees endeavour to maintain cash reserves equal to at least 12 months' operating expenditure. In addition, the trustees seek to have cash on-hand to fund promising research opportunities as they arise. Typically, this results in the Charity carrying cash reserves in excess of its 12 months' operating expenditure. As with most diseases, scientific research into LAM is costly. The trustees seek to identify research where the Charity's financial resources can be best deployed for a positive impact.

STRUCTURE, GOVERNANCE AND MANAGEMENT

LAM Action, registered charity 1167610 (England & Wales), is a charitable incorporated organisation registered with the Charity Commission on 10 June 2016 (and created to carry on the business of the unincorporated charitable association LAM Action, registered charity 1096637). The Charity operates under the rules of its Constitution, originally dated 8 June 2016 and amended 12 June 2021 and 10 June 2023.

All Executive Committee members are trustees, elected or co-opted from the members of LAM Action, and are primarily women with LAM, their relatives, doctors, healthcare workers and other interested individuals. Trustees are unpaid volunteers. LAM Action's Constitution calls for one Chair or two Co-Chairs, a Secretary and a Treasurer, chosen from amongst the members of the Executive Committee.

Upon appointment and thereafter annually, Executive Committee members are required to certify that they are not ineligible to serve as trustees based on the criteria set out in the Charities Act. LAM Action's Constitution calls for one-third of the Executive Committee, plus any trustees co-opted since the prior annual meeting of members, to step down on an annual basis, although they are eligible for re-election or re-appointment.

The Executive Committee met on eight occasions in 2025 and conducted additional business by telephone and email.

FUTURE PLANS

The LAM Action Executive Committee and our LAM Action Co-ordinator will continue to carry out activities in line with our four key objectives outlined above, whilst also aiming to evolve the Charity to support the changing needs of our membership and strengthen the financial foundation of the Charity.

We continue to evaluate the Charity's resources, volunteer capabilities, services and governance, with a view to addressing the priorities of the Charity's members, as well as the constraints the Charity currently faces as an organisation run almost entirely by volunteers.

This report was approved by the trustees on 22 April 2026 and signed on their behalf by:

Joanne (Jo) Pisani
Co-Chair and trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF LAM ACTION

I report to the Charity trustees on my examination of the accounts of the Charity for the year ended 31st December 2025.

Responsibilities and basis of report

As the Charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- accounting records were not kept in respect of the Charity as required by Section 130 of the Act; or
- the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Andrew J Davies FCA
Kneeshaws Chartered Accountants
Fourth Floor, St James House
St James Row
Burnley
BB11 1DR

27th May 2026

LAM Action – Year ended 31 December 2025

RECEIPTS ACCOUNT

	2025 £	2024 £
Receipts		
Donations and Legacies		
Donations	28,086	23,052
Other Receipts		
Fundraising	28,987	57,254
Research donations	79,218	-
Gift Aid	14,341	2,007
Sales	1,000	902
Investment Income		
Interest on cash deposits	5,977.26	6,178
Total Receipts	**157,609**	**89,392**

LAM Action – Year ended 31 December 2025

PAYMENTS ACCOUNT

	2025 £	2024 £
Payments		
Research	20,000	-
Research Salaries	73,618	30,344
Patient Support Salary	4,640	4,512
Fundraising Costs	3,928	6,373
Co-ordinator Salary	4,640	4,512
Audit and Accountancy Fees	240	510
Public Relations Costs	792	360
Bank Fees	60	66
AGM Costs	2,837	3,201
Merchandise	346	480
Travel	-	13
Postage	624	558
Printing and Stationery	396	563
Telephone and Internet	235	233
General Expenses	20	60
Subscriptions	889	746
Insurance	663	523
IT Software and Consumables	1,164	1,835
Repairs and Maintenance	-	110
Website	591	538
Legal Fees	-	2,280
Total Payments	**115,683**	**57,816**
Net Income / (Deficit)	41,926	31,576
Cash Funds Last Year End	280,598	249,022
Cash Funds This Year End	**322,524**	**280,598**

LAM Action – Year ended 31 December 2025

STATEMENT OF ASSETS AND LIABILITIES

	2025 £	2024 £
Cash Funds		
CAF Deposit Account	53,518	52,503
CAF Current Account	129,520	94,389
LAM Action PayPal	299	299
Nationwide Savings	35,000	35,000
Petty Cash	271	314
United Trust 100 Day Notice	102,114	98,094
Sum Up	1,801	-
Total Cash Reserves	**322,524**	**280,598**

These accounts on pages 7-9 were approved by the trustees on 22 April 2026 and signed on their behalf by:

Sarah Sharples
Treasurer and trustee

NOTES TO THE FINANCIAL STATEMENTS

1. **Basis of preparation**
   These accounts have been prepared on the Receipts and Payments basis in accordance with the Charities Act 2011.

2. **Taxation**
   - The Charity is not liable to tax on its charitable activities.
   - The Charity is not registered for VAT. Irrecoverable VAT is included in the expense to which it relates.