

LAM Action

Charity Number 1167610

Annual Report and Financial Statements

Year ended 31 December 2023

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Leanne Lillywhite-Sutton, Chair Sarah Sharples, Treasurer Kelly Vance, Secretary Adam Davidson (co-opted November 2023) Harriet Davidson, née Saunders Tess Hill Gillian Hollis Simon Johnson Ilona Leighton-Goodall David Mercer Sally Merritt-Collins Joanne (Jo) Pisani John Wood
Principal address	c/o Jill Pateman LAM Action PO Box 10933 Newark NG24 9QG
Registered Charity Number	1167610
Independent Examiner	M R Heaton FCCA FCIE DChA KM Business Solutions Ltd 1 st Floor, Block C The Wharf Manchester Road Burnley BB11 1JG

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 2023.

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, trade name Rapamune) 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 2023 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 via LAM Action's private email and social media groups.

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 runs the National Centre for LAM in Nottingham. Although the National Centre for LAM is independent of LAM Action, the Charity frequently interacts with the Centre 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 National Centre for LAM 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 2023. Over the last year, Dr Clements worked 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. A research paper based on this work is expected to be published in 2024.

In light of Professor Johnson's role at the National Centre for LAM 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 letter to LAM Action in 2023, Professor Renshaw noted that Dr Clements' 2023 report "shows significant progress in a number of areas and suggests that the next years are going to be highly productive, following up on many leads. The overarching aim is to identify new drugs for people with LAM and this lab would seem to have some exciting leads in that direction."

In addition to funding research, LAM Action solicits its members and otherwise offers patient input into various research initiatives. For example, in 2023, Professor Johnson sought input from LAM Action in connection with the preparation and submission of a successful consortium grant application for a research and translation centre for respiratory rare diseases, including LAM. The aim is that the centre will become the foundation for fast-tracking rare respiratory disease therapies. Patient involvement and engagement were critical components of the application and 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 National Centre for LAM, as well as other patient and scientific groups worldwide. LAM Action encourages its members who have LAM to participate in treatment trials, tissue donation and other studies and research wherever this is feasible and in their best interests. For example, in 2023 the Charity informed people subscribed to our private social media group of two studies being conducted in the United States in which women with LAM in the United Kingdom might be eligible to participate.

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 2023 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 age-related and regional peer-support groups, to help the LAM community interact with each other and discuss shared experiences and concerns.
- Continuing to facilitate communication between women with LAM through the private LAMline email support chat group and closed Facebook group LAM Talk UK.
- 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 in June 2023, for people with LAM and their families to hear about LAM research and hear from people with the disease.

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- 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 Ride London, 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 The LAM Foundation in the United States and LAM Australia, through sharing information, experiences and best practices.

FINANCIAL REVIEW

Revenues and Expenses for 2023

Total income of £102,582 was up significantly in 2023 compared to £65,463 in 2022. This was due largely to several significant donations from individual donors, key fundraising events such as the London Marathon and Ride London and timing variances in Gift Aid receipts in 2023 compared to 2022.

Expenses of £63,955 were slightly less in 2023 compared to £69,969 in 2022, with the difference due primarily to timing variances in invoiced research salaries. Net income of £38,627 in 2023 compared favourably to an operating deficit in 2022 of £4,506.

Reserves policy

Reserves stood at £249,022 at 31 December 2023. The trustees endeavour to maintain cash reserves equal to at least 12 months' operating expenditure. The Charity continues to evaluate research opportunities, other expenditures and funding sources in an effort to utilise and manage our reserves going forward.

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 five occasions in 2023 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.

In late 2023 we began a thorough evaluation of the Charity's resources, volunteer capabilities, services and governance, with a view to developing a strategic plan that addresses the priorities of the Charity's

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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 13 April 2024 and signed on their behalf by:

Leanne Lillywhite-Sutton
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 2023.

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.

M R Heaton FCCA FCIE DChA
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16 October 2024

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RECEIPTS ACCOUNT

	2023 £	2022 £
Receipts		
Donations and Legacies		
Donations	47,836	38,598
Other Receipts		
Fundraising	31,373	23,015
Gift Aid	17,949	637
Sales	1,022	1,093
Investment Income		
Interest on cash deposits	4,401	2,120
Total Receipts	102,582	65,463

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PAYMENTS ACCOUNT

	2023 £	2022 £
Payments		
Research Salaries	46,548	54,162
Patient Support Salary	4,333	4,327
Fundraising Costs	3,195	2,776
Co-ordinator Salary	4,333	4,327
Staff Training	1,280	-
Accountancy Fees	-	240
Bank Fees	72	93
AGM Costs	656	480
Merchandise	465	465
Travel	100	-
Printing and Postage	963	315
Telephone and Internet	213	745
General Expenses	22	178
Sundries		126
Subscriptions	286	-
Insurance	491	458
IT Software and Consumables	503	1169
Website	495	108
Total Payments	63,955	69,969
Net Income / (Deficit)	38,627	(4,507)
Cash Funds Last Year End	210,395	214,902
Cash Funds This Year End	249,022	210,395

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STATEMENT OF ASSETS AND LIABILITIES

	2023 £	2022 £
Cash Funds		
CAF Deposit Account	51,228	50,285
CAF Current Account	68,286	33,647
LAM Action PayPal	299	306
Nationwide Savings	35,000	35,000
Petty Cash	170	254
United Trust 100 Day Notice	94,039	90,904
Total Cash Reserves	249,022	210,395

These accounts on pages 7-9 were approved by the trustees on 13 April 2024 and signed on their behalf by:

Sarah Sharples
Treasurer and trustee

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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.