

LAM Action

Charity Number 1167610

Annual Report and Financial Statements

Year ended 31 December 2022

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Leanne Lillywhite-Sutton, Chair Sarah Sharples, Treasurer Kelly Vance, Secretary Tess Hill (co-opted July 2022) Gillian Hollis Simon Johnson Ilona Leighton-Goodall David Mercer Sally Merritt-Collins Heather Mills (resigned 8 March 2022) Joanne (Jo) Pisani Harriet Saunders (co-opted 2 April 2022 and elected 11 June 2022) 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 2022.

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 and affects approximately 10 in every million. 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.

There was a very significant breakthrough for women with LAM around 2010 when it was 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.

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 Coordinator, Jill Pateman. All other activities are conducted entirely through the contribution of volunteers.

In 2022, 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

25-Year History

The year 2022 marked the 25th anniversary of LAM Action (including its predecessor organisations). Over the course of 25 years, more than £1.5 million has been raised to fund important research and clinical trials and support hundreds of people with LAM and their families. The achievements of LAM

LAM Action – Year ended 31 December 2022

Action, and the advancements in scientific knowledge about LAM, were celebrated at the Charity's annual meeting in June 2022. Our meeting included presentations from Professor Emeritus Anne Tattersfield, Professor Simon Johnson, Dr Debbie Clements and Dr Lisa Henske and messages of support from LAM patient groups around the world.

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 benefits greatly from Professor Johnson's expertise and stature as an expert in LAM. In 2022, one of LAM Action's Executive Committee members presented LAM Action's and the patients' perspective at the annual clinical review of the National Centre for LAM by NHS England Highly Specialised Services.

In addition to providing comprehensive clinical care for women with LAM, the National Centre for LAM facilitates research work on LAM. For example, in 2022 Professor Johnson's research group was awarded several grants related to their ongoing LAM research.

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 2022. Over the last year, Dr Clements worked primarily on research into 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.

In light of Professor Johnson's role at the National Centre for LAM and his role as a trustee of LAM Action, historically the Charity has asked an independent scientific advisor to evaluate ongoing research. In 2022, Professor Stephen Renshaw agreed to serve as the independent scientific advisor, following the retirement of Professor Ian Sabroe who had served in that role previously. Professor Renshaw noted that the work conducted by Professor Johnson's research team "has the potential to increase understanding of the disease process and to identify better treatments" and concluded that "high-quality work has been performed and LAM Action would seem to be spending its money wisely".

In addition, LAM Action solicits its members and otherwise offers patient input into various research initiatives. For example, in 2022, Professor Johnson sought input from LAM Action regarding a rare disease grant application to the Medical Research Council to improve rare disease care and research. In addition, in an effort to share best practices and experience, LAM Action initiated contact with The Myrovlytis Trust, which provides research and patient support into another rare cystic lung disease, Birt-Hogg Dube Syndrome.

Treatment trials, studies and research into LAM are taking place around the world. 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.

LAM Action keeps abreast of developments in LAM research through its links with the medical team at the National Centre for LAM, as well as other patient and scientific groups worldwide.

Support and information for those affected by LAM

The Charity works hard to develop the information and emotional support provided to those with LAM and their families. Initiatives undertaken during 2022 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.

LAM Action – Year ended 31 December 2022

- Continuing to facilitate communication between women with LAM through the private LAMline email support chat group and closed Facebook group LAM Talk UK.
- Holding an information session for volunteers who provide one-to-one support to others with LAM.
- 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 2022, for people with LAM and their families to hear about LAM research, hear from people with the disease and celebrate the Charity's 25th anniversary.
- 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 electronic filing 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 and materials and participating in each other's events.

FINANCIAL REVIEW

Revenues and Expenses for 2022

Total income of £65,464 was up significantly in 2022 compared to £44,647 in 2021. This was due largely to several significant donations from individual donors and the return (post-lockdown) in 2022 of key fundraising events such as the London Marathon and Ride London.

Expenses in 2022 were largely consistent with 2021, with a small difference due largely to timing variances in invoiced research salaries. Total expenditures of £69,970 exceeded total income of £65,464 by £4,506, compared to a shortfall in 2021 of £20,238. The shortfall was paid from reserves, which at 31 December 2022 stood at £210,395. The Charity continues to look at funding sources and expenditures in an effort to preserve cash reserves going forward.

Reserves policy

The trustees endeavour to maintain cash reserves equal to at least 12 months' operating expenditure.

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.

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 2022 and conducted additional business by telephone, email and sub-groups.

FUTURE PLANS

The LAM Action Executive Committee and our LAM Action Coordinator 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.

Our immediate aims focus on continuing to support people with LAM and their families and being able to continue funding research into the disease. In 2023, we intend to evaluate how best to achieve these aims. In particular, the current fundraising climate is challenging largely due to ongoing inflation and the lingering effects of the Covid-19 pandemic. We aim to develop a strategy to keep the Charity on a strong financial footing going forward.

This report was approved by the trustees on 20 May 2023 and signed on their behalf by:

Leanne Lillywhite-Sutton
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 2022.

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
KM Business Solutions Limited
1st Floor, Block C,
The Wharf
Burnley
Lancashire
BB11 1JG

20 May 2023

LAM Action – Year ended 31 December 2022

RECEIPTS ACCOUNT

	2022	2021
	£	£
Receipts		
Donations and legacies		
Donations	38,598	32,894
Other Receipts		
Fundraising	23,015	10,983
Gift Aid	637	0
Sales	1,093	743
Investment income		
Interest on cash deposits	2,120	27
Total Receipts	65,464	44,647

LAM Action – Year ended 31 December 2022

PAYMENTS ACCOUNT

	2022 £	2021 £
Payments		
Charitable Expenditure		
Research Salaries	54,162	47,424
Patient Support Salary	4,327	4,177
Fundraising Costs	2,776	3,542
AGM Costs	480	0
Purchases	465	281
Public Relations	0	180
Bank Charges	93	132
Coordinator Salary	4,327	4,177
Website	108	2,712
Insurance	458	427
IT Software and Consumables	1,169	984
Telephone	178	176
Postage and Stationery	1,060	392
Sundries	126	40
Accountancy Fee	240	240
 Total payments	69,970	64,884
 Net of receipts/(payments)	(4,506)	(20,237)
 Cash funds last year end	214,902	235,139
 Cash funds this year end	210,395	214,902

LAM Action – Year ended 31 December 2022

STATEMENT OF ASSETS AND LIABILITIES

Cash Funds	2022 £	2021 £
CAF Bank	33,647	40,323
CAF Deposit Account	50,285	50,093
Paypal	306	233
Petty Cash	254	242
Nationwide	35,000	35,000
United Trust	90,904	89,011
Total Cash Reserves	210,395	214,902

These accounts on pages 7 and 8 were approved by the Trustees on 20 May 2023 and signed on their behalf by:

Sarah Sharples - Treasurer

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.