

LAM Action

Charity Number 1167610

Annual Report and Financial Statements

Year ended 31 December 2021

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Leanne Lillywhite-Sutton, Chair Sarah Sharples, Treasurer Kelly Vance, Secretary Gillian Hollis Simon Johnson Ilona Leighton-Goodall David Mercer Sally Merritt-Collins Heather Mills (resigned 8 March 2022) Jo Pisani Harriet Saunders (co-opted 2 April 2022) Anne Tattersfield (resigned 20 October 2021) 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 2021.

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.

Due to the ongoing COVID-19 pandemic, LAM Action and our volunteers carried out most person-to-person interactions on a 'virtual' basis (via Zoom/Microsoft Teams) and over the telephone in 2021. However, we believe that by adapting to this virtual method of communication we have supported more people in more parts of the country than pre-pandemic, when many of the Charity's activities were based on physical gatherings.

ACHIEVEMENTS AND PERFORMANCE

Advancing research and educating health professionals

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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 addition to providing comprehensive clinical care for women with LAM, the National Centre for LAM facilitates research work on LAM.

In February 2021, two members of LAM Action's Executive Committee presented LAM Action's and the patients' perspective at the annual ('virtual') clinical review of the National Centre for LAM by NHS England Highly Specialised Services. One of the topics they highlighted was the close coordination between LAM Action and the National Centre for LAM over the prior 12 months in connection with the COVID-19 pandemic and communications to LAM Action's members.

For nearly 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 2021. Over the last year, Dr Clements has 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 recent years, Professor Ian Sabroe, Professor of Inflammation Biology, University of Sheffield and Co-Director, Medical Humanities Sheffield, has conducted that evaluation. Professor Sabroe retired in 2021 and LAM Action is seeking a replacement for the role of independent scientific advisor. The Charity notes that Dr Clements' work is reflected in two of six papers published on LAM by Professor Johnson's research team in 2021 and Dr Clements won the Wendy Stannard prize for best oral presentation in November 2021 for her presentation on LAM research to over 120 researchers and clinicians in the East Midlands at the Joint Respiratory Research Conference.

At the instigation of one of LAM Action's trustees, LAM featured in a report published by the medical charity LifeArc and law firm Pinsent Masons on new uses for existing medicines. The report highlighted how repurposing of the drug sirolimus has transformed the lives of many women with LAM.

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 the year by LAM Action's Executive Committee and other volunteers included:

- Creating a new LAM Action website, one of the key aims of which is to direct those who are newly diagnosed with LAM to sources of information and support.
- Creating a new, updated factsheet about LAM, which is available to download from LAM Action's website.
- Creating flyers about LAM and pregnancy and LAM and flying, which are available to download from LAM Action's website.
- With the assistance of a mental health professional who volunteered her time, producing videos for those who are newly diagnosed with LAM and for those who have had LAM for some time, focussing on the mental health aspects of such a diagnosis and of living with the disease.
- In conjunction with the National Centre for LAM, communicating with our members and the LAM community about COVID-19, including recommendations with respect to vaccines.

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- Providing one-to-one support to women with LAM, particularly to those newly diagnosed. Support is also provided to the family members of women 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, which met on a 'virtual' basis in 2021.
- Continuing to facilitate communication between women with LAM through the private LAMline email support chat group and closed Facebook group LAM Talk UK.
- Conducting training sessions for volunteers who provide one-to-one support to others with LAM, and providing related guidance, policies and procedures for use within these one-to-one support roles.
- Arranging the Charity's AGM and annual meeting on a 'virtual' basis in June 2021, for people with LAM and their families to hear about LAM research and developments with COVID-19.
- Continuing to produce our newsletter LAMPost three times per year, which includes a variety of stories, including personal profiles, medical news related to LAM, practical tips for living with the disease and 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, through sharing information and materials and participating in each other's events.

FINANCIAL REVIEW

Revenues and Expenses for 2021

Donations and fundraising were down significantly in 2021 compared to 2020. The Charity believes that this was due largely to four factors: (i) the ongoing impact of the COVID-19 pandemic, with the London Marathon being the only major fundraising event for the Charity in 2021, (ii) a timing variance in receiving Gift Aid reclaimed on donations, (iii) the inclusion in our 2020 accounts of an £8,344 Covid National Lottery Grant and (iv) the inclusion in our 2020 accounts of a £10,000 bequest to LAM Action.

The amount of our expenses in 2021 was largely consistent with 2020. We continued to employ our LAM Action Coordinator on a home-working basis, paid for public relations only on an "as needed" basis rather than a retainer and exhausted our old stock of Christmas cards rather than invest in new stock. We continue to look to these and other ways in which the Charity might be able to make cost-savings as compared to prior years.

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 to allow for the conduct of annual and other meetings of members on a virtual or hybrid basis.

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

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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 ‘virtually’ on four occasions in 2021 and conducted additional business by telephone, email and sub-groups.

FUTURE PLANS

The year 2022 marks LAM Action’s 25th anniversary. In that time, we have raised over £1.5 million, funded important research and clinical trials and supported hundreds of women with LAM and their families. 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.

Many of our immediate aims focus on providing support to people with LAM and their families. Throughout 2020 and much of 2021 and due largely to the COVID-19 pandemic, we experienced a large increase in demand from our membership for varying types of support via our closed Facebook group (LAM Talk UK) and our private email support group (LAMline). We also experienced more requests for, and participation in, both one-to-one support and peer-group support. Prior to the pandemic, in-person support had been the norm, but throughout the last two years almost all our support has been on a ‘virtual’ basis. This has allowed people for whom an in-person meeting was not feasible previously to access support using virtual technologies. Having seen this benefit, we intend to continue to make our support offering available on a ‘virtual’ and, as conditions permit, an in-person basis.

In 2021, LAM Action’s founder and long-standing trustee, Professor Emeritus Anne Tattersfield, stood down from our Executive Committee and another trustee also stepped down due to personal reasons. LAM Action continues to look to recruit trustees who can assist the Charity as we address fundraising challenges and the desire to have additional representatives from the medical community on our Executive Committee.

The current fundraising climate is challenging due to rising inflation and the ongoing effects of the pandemic. We intend to pursue other avenues of funding for LAM Action during 2022-2023. This might include retaining a consultant to assist us in identifying and working with potential foundations and other donors.

This report was approved by the trustees on 5 May 2022 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 2021.

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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18 May 2022

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RECEIPTS ACCOUNT

	2021 £	2020 £
Receipts		
Donations and legacies		
Donations	32,894	44,397
Donations towards AGM	0	0
Other Receipts		
Fundraising	10,983	25,567
Gift Aid	0	7,535
Sales	743	140
Grant Income	0	8,344
Investment income		
Interest on cash deposits	27	2,781
Total Receipts	44,647	88,765

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PAYMENTS ACCOUNT

	2021 £	2020 £
Payments		
Charitable Expenditure		
Research Salaries	47,424	47,071
Patient Support Salary	4,177	4,172
Fundraising Costs	3,542	5,139
AGM Costs	0	0
Travel	0	53
Public Relations	180	1,748
Bank Charges	132	60
Coordinator Salary	4,177	4,172
Rent	0	0
Insurance	427	418
IT Software and Consumables	984	999
Telephone	176	226
Postage and Stationery	392	489
Sundries	40	144
Cost of Goods (Christmas cards to sell)	281	
Accountancy Fee	240	240
Website Consultant Fee	2,712	0
 Total payments	64,884	64,930
 Net of receipts/(payments)	(20,237)	23,835
 Cash funds last year end	235,139	210,795
 Cash funds this year end	214,902	235,139

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STATEMENT OF ASSETS AND LIABILITIES

Cash Funds	2021 £	2020 £
CAF Bank	40,323	60,460
CAF Deposit Account	50,093	50,088
Paypal	233	268
Petty Cash	242	312
Nationwide	35,000	35,000
United Trust	89,011	89,011
Total Cash Reserves	214,902	235,139
 Liabilities		
Wages	3,281	3,281

These accounts on pages 7 and 8 were approved by the Trustees on 5 May 2022 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.