

LAM ACTION

England & Wales · Charity number 1167610

Details

Status Registered

Legal form CIO

Registered 2016-06-10

Register [View on the Charity Commission register](#)

Contact

Address 6 Brun Crescent
Clitheroe
Lancashire
BB7 2FJ

Phone 07710 527636

Email finance@office.lamaction.org

Website <http://lamaction.org>

Activities

Objects: 1) TO PROVIDE SUPPORT AND INFORMATION FOR THOSE WITH LYMPHANGIOLEIOMYOMATOSIS ("LAM") AND THEIR FAMILIES; 2) TO SUPPORT RESEARCH WHICH FURTHERS UNDERSTANDING OF LAM, INCLUDING THE CAUSE OF LAM AND POTENTIAL TREATMENT FOR LAM IN ACCORDANCE WITH REGULATORY REQUIREMENTS; 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.

Activities: LAM Action's main objectives are to: provide support and information for those with lymphangioleiomyomatosis (?LAM?) and their families; support research which furthers understanding of LAM; increase awareness amongst health professionals about LAM and promulgate good clinical practice for its management; and share research, clinical and patient support experience in the UK and overseas.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£89,392	£57,816	-	-
2023-12-31	£102,582	£63,955	-	-
2022-12-31	£65,464	£69,970	-	-
2021-12-31	£44,647	£64,884	-	-
2020-12-31	£88,765	£64,930	-	-

Trustees

Name	Role	Appointed
Adam James Davidson		2023-11-01
Alison Hilary Bronwen Merritt-Collins		2018-11-26
Clare Elizabeth Lyon		2025-02-08
DAVID ARTHUR MERCER		2016-06-10
GILLIAN ELIZABETH HOLLIS		2016-06-10
JOHN DAVID WOOD		2016-06-10
Joanne Patra Pisani		2019-11-04
KELLY VANCE		2016-06-10
PROFESSOR SIMON RICHARD JOHNSON		2016-06-10
SARAH LOUISE SHARPLES		2016-06-10
Stephanie Jane Evans		2025-10-15

LAM ACTION

England & Wales - Charity number 1167610

Accounts

LAM Action

Charity Number 1167610

Annual Report and Financial Statements

Year ended 31 December 2024

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Leanne Lillywhite-Sutton, Chair Sarah Sharples, Treasurer Kelly Vance, Secretary Adam Davidson Harriet Davidson Tess Hill Gillian Hollis Simon Johnson Ilona Leighton-Goodall Clare Lyon (co-opted February 2025) 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	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 2024.

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 2024 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 Birmingham. LAM Action had 210 members at 31 December 2024, 63% 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 2024. 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. A research paper based on this work was published in 2024.

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 June 2024 report, Professor Renshaw noted that Dr Clements' research "represents a valuable contribution to the field that is taking important steps towards translation. It would seem likely that further progress will continue to be made by continuing along the direction indicated in the application. Given the focus on drug repurposing, this would seem the most rapid approach to making a difference to people with LAM."

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 2024. 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 2024 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 nine times in 2024.
- Continuing to facilitate communication between women with LAM, primarily through the closed Facebook group LAM Talk UK, which had 211 members at 31 December 2024, 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.

LAM Action – Year ended 31 December 2024

- 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 2024 55 people attended our first in-person annual meeting since our pre-Covid June 2019 meeting.
- 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 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 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 2024

Total income of £89,392 was down in 2024 compared to £102,582 in 2023. This was due primarily to timing variances in Gift Aid receipts in 2024 compared to 2023. Our income also reflected a £24,784 reduction in donations in 2024 compared to 2023, which was offset by a £25,881 increase in fundraising in 2024 compared to 2023.

Expenses of £57,816 were slightly less in 2024 compared to £63,954 in 2023. This was due largely to timing variances in £16,204 of invoiced research salaries. Other costs were up in 2024 compared to 2023, largely attributable to expenses associated with the Charity's in-person annual meeting in 2024 (£3,201); legal fees to review the Charity's policies (£2,280); and expenses associated with the Charity's fundraising activities, such as payments charged by fundraising platforms such as JustGiving.

Reserves policy

Reserves stood at £280,598 at 31 December 2024. 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.

LAM Action – Year ended 31 December 2024

The Executive Committee met on four occasions in 2024 and conducted additional business by telephone and email. In 2024 and with the assistance of counsel, the Charity commenced a review of our policies and procedures, which will continue over the coming year. In addition, the Charity self-audited the skills and capabilities of our trustees in order to identify areas where we might look to recruit other volunteers or paid support to assist the Charity.

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 10 May 2025 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 2024.

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



16th May 2025

LAM Action – Year ended 31 December 2024

RECEIPTS ACCOUNT

	2024 £	2023 £
Receipts		
Donations and Legacies		
Donations	23,052	47,836
Other Receipts		
Fundraising	57,254	31,373
Gift Aid	2,007	17,949
Sales	902	1,022
Investment Income		
Interest on cash deposits	6,178	4,401
Total Receipts	89,392	102,582

LAM Action – Year ended 31 December 2024

PAYMENTS ACCOUNT

	2024 £	2023 £
Payments		
Research Salaries	30,344	46,548
Patient Support Salary	4,512	4,333
Fundraising Costs	6,373	3,196
Co-ordinator Salary	4,512	4,333
Staff Training	-	1,280
Audit and Accountancy Fees	510	-
Public Relations Costs	360	-
Bank Fees	66	72
AGM Costs	3,201	656
Merchandise	480	465
Travel	13	100
Postage	558	619
Printing and Stationery	563	341
Telephone and Internet	233	213
General Expenses	60	22
Subscriptions	746	286
Insurance	522	491
IT Software and Consumables	1,835	503
Repairs and Maintenance	110	-
Website	538	495
Legal Fees	2,280	-
Total Payments	57,816	63,954
Net Income / (Deficit)	31,576	38,627
Cash Funds Last Year End	249,022	210,395
Cash Funds This Year End	280,598	249,022

LAM Action – Year ended 31 December 2024

STATEMENT OF ASSETS AND LIABILITIES

	2024	2023
	£	£
Cash Funds		
CAF Deposit Account	52,503	51,228
CAF Current Account	94,389	68,286
LAM Action PayPal	299	299
Nationwide Savings	35,000	35,000
Petty Cash	314	170
United Trust 100 Day Notice	98,094	94,039
Total Cash Reserves	280,598	249,022

These accounts on pages 7-9 were approved by the trustees on 10 May 2025 and signed on their behalf by:

Sarah Sharples
Treasurer and trustee

LAM Action – Year ended 31 December 2024

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.

LAM ACTION

England & Wales - Charity number 1167610

Accounts

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.

LAM Action – Year ended 31 December 2023

- 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

LAM Action – Year ended 31 December 2023

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

16 October 2024

LAM Action – Year ended 31 December 2023

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

LAM Action – Year ended 31 December 2023

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

LAM Action – Year ended 31 December 2023

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

LAM Action – Year ended 31 December 2023

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.

LAM ACTION

England & Wales - Charity number 1167610

Accounts

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.

LAM ACTION

England & Wales - Charity number 1167610

Accounts

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

LAM Action – Year ended 31 December 2021

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.

LAM Action – Year ended 31 December 2021

- 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

LAM Action – Year ended 31 December 2021

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

18 May 2022

LAM Action – Year ended 31 December 2021

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

LAM Action – Year ended 31 December 2021

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

LAM Action – Year ended 31 December 2021

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.

LAM ACTION

England & Wales - Charity number 1167610

Accounts

LAM Action

Charity Number 1167610

Annual Report and Financial Statements

Year ended 31 December 2020

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Leanne Lillywhite-Sutton Gillian Hollis Sarah Sharples Simon Johnson David Mercer Anne Tattersfield Kelly Vance John Wood Ilona Leighton-Goodall Sally Merritt-Collins Heather Mills Jo Pisani
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 2020.

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 seven 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 of childbearing age and usually progresses over time, although the rate at which it progresses varies considerably between individuals. Most women with LAM experience breathlessness, particularly on exertion. Over time, many women require supplemental oxygen. Some women require lung transplants and, tragically, some face end-stage disease.

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 2020, the direct role of volunteers, with support from the LAM Action Coordinator, was concentrated in numerous ways (always in support of the four main objectives above), with various adaptations being made to our methods of communication and support in light of the Covid-19 pandemic. Many person-to-person interactions took place virtually (via Zoom/MS Teams) or over the phone.

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 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 many 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 2020, although support was not provided during periods of the year when Dr Clements was furloughed due to Covid-

LAM Action – Year ended 31 December 2020

19 restrictions. 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, the Charity has asked an independent scientific advisor, Professor Ian Sabroe, to evaluate ongoing research that LAM Action may fund. Professor Sabroe is Professor of Inflammation Biology, University of Sheffield and Co-Director, Medical Humanities Sheffield.

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 women with LAM and their families. Initiatives undertaken during the year by LAM Action's Executive Committee and other volunteers included:

- Updating on a regular basis LAM Action's website and Facebook pages, allowing improved communication between LAM Action and others.
- In conjunction with the National Centre for LAM, communicating with our members and the LAM community about Covid-19, including recommendations with respect to shielding and vaccines.
- Preparing or updating factsheets about LAM and other pertinent materials, which may be requested from the LAM Action Coordinator or downloaded from LAM Action's website.
- 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.
- Launching age-related peer-support groups, which met on a 'virtual' basis to discuss shared experiences and concerns.
- Continuing to provide 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 2020.
- Arranging a 'virtual' 'meeting in June for people with LAM and their families, to hear about LAM research and developments with Covid-19.
- Holding the Charity's AGM in September, which was held on a 'virtual' basis due to the Covid-19 pandemic, as agreed with the Charities Commission.
- Continuing to produce our newsletter LAMPost three times per year, which includes a variety of stories, ranging from personal profiles, medical news related to LAM and practical suggestions for fundraising and living with the disease.
- Continuing to facilitate communication between women with LAM through the private LAMline email support chat group and closed Facebook group LAM Talk UK.
- Deciding to waive membership fees to join LAM Action, on the basis that we did not want anyone affected by LAM to be discouraged to join the Charity by reason of a (relatively modest) fee.
- Updating our electronic filing systems to facilitate efficient record-keeping and member outreach and support.
- Creating a brief for, and selecting, an external consultant to facilitate a training project for volunteers who provide one-to-one support to others with LAM. This training project took place between January and March 2021 and involved the consultant researching best practice, policies and procedures employed by other charities and using this research to create a training session for our own volunteers. Related guidance, policies and procedures were also produced for LAM Action volunteers to use within their one-to-one support volunteer roles.

LAM Action – Year ended 31 December 2020

- Maintaining close links with LAM patient groups internationally, particularly The LAM Foundation in the US, through sharing information and materials and participating in each other's events.

FINANCIAL REVIEW

Revenues and Expenses for 2020

Despite the cancellation of the charity sector's major fundraising events such as the London Marathon and Ride London due to the Covid-19 pandemic, LAM Action raised more in donations and fundraising in 2020 than in 2019. This was due largely to 'virtual' events held in lieu of these organised events and to bequests and gifts in memory of women with LAM who passed away.

In addition, in November 2020 the Charity was awarded a Covid-19 National Lottery Grant, to be applied toward patient support activities. LAM Action used this grant to pay the 'support' function of the LAM Action Coordinator's salary (i.e., 50% of her salary), obtain an enhanced Zoom membership for the purpose of our regional and age-related support groups' 'virtual' meetings and pay for the training project described above for LAM Action's one-to-one support volunteers.

As reflected in our 2020 financial results, we made a number of cost-savings over the past year, in particular:

- We have ceased paying rent for office space for our LAM Action Coordinator, who has now shifted to home-working.
- Our PR costs are significantly lower year on year as fundraising events have decreased and thus the need to promote them has ceased.
- Our meeting for people with LAM and our AGM costs were zero as these events took place 'virtually' as opposed to in-person in an external venue.

Reserves policy

The trustees endeavour to maintain cash reserves equal to at least 12 months' operating expenditure with any excess put towards future developments.

STRUCTURE, GOVERNANCE AND MANAGEMENT

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

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 'virtually' on five occasions in 2020 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. Many of our immediate aims focus on providing support to people with LAM and their families.

The Covid-19 pandemic led to a large increase in demand from our membership for varying types of support. There was both an influx of activity and dialogue on our closed Facebook group (LAM Talk UK) and our private email support group (LAMline). We also experienced more requests for both one-to-one support and peer-group support. This support took place 'virtually' via Zoom or over the telephone as opposed to in-person, which had previously been the norm. As we begin to emerge from the Covid-19 pandemic, we anticipate the volume of support requests will remain high. We will continue to promote our support offering, with people able to access this kind of support both 'in-person' and 'virtually', thus making it more readily accessible than it was prior to the pandemic and the widespread use of virtual technologies.

In addition, the Executive Committee is producing a mental health video for the LAM Community, which is intended to help people address the mental health aspects of a LAM diagnosis and living with LAM. We have solicited input from the LAM community regarding individual experiences and gratefully received assistance from a mental health professional. We intend to make the video available via our website in due course and to prepare written material relating to mental health and LAM.

To ensure that it remains accessible and serves as a useful guidepost to those who seek information about LAM, the Charity also is undertaking some re-design to the LAM Action website. We expect to complete the project in 2021.

We also intend to pursue other avenues of funding for LAM Action during 2021-2022. This may include retaining a consultant to assist us in identifying and working with potential foundations and other donors.

With last year being an exception due to the Covid-19 pandemic, traditionally we combine our annual meeting for people with LAM and their families with our Annual General Meeting. Due to the ongoing pandemic and with consent of the Charities Commission, we will be holding our Annual General Meeting for 2020 (and the related LAM meeting) on a virtual basis on 12 June 2021. The meeting will occur before the next phase of the government's roadmap out of lockdown, which comes into effect from 21st June. Given the nature of our Charity (representing people who have a chronic, rare lung disease, many of whom were advised to shield), we concluded that it was prudent to hold a 'virtual' gathering, given the increased risk from Covid-19 to our audience.

LAM Action looks forward to building on our achievements of the past year and continuing to support people affected by LAM and funding research into the disease.

This report was approved by the trustees on 24 May 2021 and signed on their behalf by:

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 2020.

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

27 October 2021

LAM Action – Year ended 31 December 2020

RECEIPTS ACCOUNT

	2020	2019
	£	£
Receipts		
Donations and legacies		
Donations	44,397	28,531
Donations towards AGM	0	1,013
Other Receipts		
Fundraising	25,567	17,058
Gift Aid	7,535	100
Membership Subscriptions	0	2,848
Sales	140	1,727
Grant Income	8,344	
Investment income		
Interest on cash deposits	3,290	1,819
Total Receipts	89,273	53,096

LAM Action – Year ended 31 December 2020

PAYMENTS ACCOUNT

	2020	2019
	£	£
Payments		
Charitable Expenditure		
Research Salaries	47,071	78,360
Patient Support Salary	4,172	4,043
Fundraising Costs	5,139	4,794
AGM Costs	0	4,024
Travel	53	473
Public Relations	1,748	5,238
Bank Charges	60	80
Coordinator Salary	4,172	4,042
Rent	0	2,093
Insurance	418	402
IT Software and Consumables	999	472
Telephone	226	216
Postage and Stationery	489	165
Sundries	144	135
Travel Support	0	750
Accountancy Fee	240	
Total payments	64,930	105,287
Net of receipts/(payments)	24,343	(52,191)
Cash funds last year end	210,795	262,986
Cash funds this year end	235,138	210,795

LAM Action – Year ended 31 December 2020

STATEMENT OF ASSETS AND LIABILITIES

Cash Funds	2020	2019
	£	£
CAF Bank	60,460	18,379
CAF Deposit Account	50,088	20,021
Paypal	268	882
Petty Cash	312	216
Nationwide	35,000	85,000
United Trust	89,011	86,297
Total Cash Reserves	235,138	210,795
Liabilities		
Wages	3,281	19,439

These accounts on pages 7 and 8 were approved by the Trustees on 24 May 2021 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.