

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-

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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.

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- 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
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27 October 2021

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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

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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

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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.