



Minutes of the 2<sup>nd</sup> Annual General Meeting of LAM Action  
12<sup>th</sup> June 2004

Chair - Lucy Falconer

The Annual General Meeting held at the Nottingham City Hospital was attended by 60 patients and guests.

1. CHAIRPERSON'S REPORT

Lucy reported that many things have been happening but said she would focus on one particularly exciting area, the move towards a more international approach, both scientifically and in terms of communication for both patients and doctors.

She emphasised the following:

- that the guest speaker was Dr Joel Moss, Chief Pulmonologist, NHLBI, Bethesda, United States, who runs the NIH Protocol for LAM
- that Michelle Gonsalves, President of FLAM (Association France Lymphangioliolomyomatose – the French Lam Society) was attending. Michelle had organised a meeting of Eurolam in October 2003 in Paris and we hope to build on this later in the year
- the funding obtained from the government in the US for the Clinical Research Network, based in Cincinnati, but covering other centres in the US and Europe including Nottingham
- the survey about flying, which has been sent to patients in seven European countries
- the Eurolam Meeting planned for September 2004 in Nottingham

The international approach is important – we are a very small group: a disease is considered rare if there are thousands of patients in a country the size of France, but there are only about 100 LAM patients in the UK, perhaps 120 in France. However the need is very GREAT.

2. TREASURER'S REPORT

The trustees are the current members of the Executive Committee.

Overview of finances March 2003 to 30 April 2004

For historical reasons our funds are held in three separate accounts:

- our HSBC bank account – into which all new monies are now paid. The account was opened 18 months ago when LAM Action was registered as an independent charity. The balance at 30<sup>th</sup> April was £36 k

- the LAM Trust Fund – which is our original trust fund held as part of the City Hospital Charitable Funds. £4k remains in this fund and will be used to keep the office running for the next 12-18 months. The Trust Fund will be closed when all our money has been used.
- our University of Nottingham account. The reason for this is that both our researcher, Debbie Clements, and our co-ordinator, Jan Johnson, are employed by the university. The university invoices us and funds are transferred to the university account. Currently £2k held in the account.

The total balance at 30<sup>th</sup> April was £42 k

#### Main income categories included

- personal donations including all personal fundraising as well as gifts of money - £12k
- the 2<sup>nd</sup> and final instalment of the research grant from the Charles Hayward Foundation - £10k
- a legacy from Miss Dorothy Craig, an English lady who lived in New Zealand. The actual legacy was for £10k with the understanding that the money was shared with the NZ LAM Trust for research - £5k
- Flora London Marathon sponsorship which was down last year due to injury - £2.5k
- corporate donations including donations from employers whose policy is to match funds raised for charity by their staff, notably the Royal Bank of Scotland (thanks to Audrey Ferguson) and Barclays Bank (thanks to Mark Fullerton) - £2k
- charitable donations including a donation of £1,000 from the Yorkshire Building Society Charitable Trust for printing costs - £1.6k
- sales of Christmas cards £1k
- tax reclaims – this was mentioned as a reminder of the value of Gift Aid declarations by tax payers. No figure was available as yet.

#### Main areas of expenditure included

- the salary of our researcher - £32k
- running costs including: our co-ordinator's salary, postage, office consumables and costs of the annual meeting (excluding any sponsorship) - £2.3k
- PR and promotional materials including printing our Christmas cards and £1.5k for 5 Gold Bond places in the London Marathon - £3k

#### Looking ahead

Our income last year was £43.5k  
Our expenditure was £39.5

This left us with an excess of £4k but we have to remember that last year's total included £15k from the grant and the legacy

### 3. ELECTION OF EXECUTIVE COMMITTEE AND OFFICERS

Lucy reported that the Treasurer had resigned and thanked Jane Ward for all the work she has done for LAM Action, particularly in the early days of the LAM Trust. No nominations for membership had been received apart from the rest of the present Committee who were willing to be re-elected and this was agreed by the meeting. This left three vacancies on the Executive Committee,

and she encouraged people to put their names forward, pointing out that there are currently no representatives from the north of England or Scotland.

4. ANY OTHER NOTIFIED BUSINESS – none

5. DATE OF NEXT MEETING

Saturday 11<sup>th</sup> June 2005