



## *Life with LAM*

In the first issue of the newsletter we asked for contributions from all readers, sufferers, members of their families, anybody really, who could throw some light on the different ways LAM can affect us all. We are delighted to include below, a letter from Theresa Hewat describing her trials, and triumphs, with LAM. We make no apology for including this letter in full.

In addition we include a short letter from a friend of Theresa who lives in France (name unknown), obviously the medical implications are not fully discussed, but we should not ignore anything which may contribute in a positive way to the debate, finally there is what I suppose you could describe as a 'plug' for the LAM protocol of the National Institute of Health (Maryland USA) brought to us by Lucy Falconer of Aylesbury, again the thought is that access to information harms no-one and benefits all.

## *Fund-raising Fiona*

Ten year old Fiona Hutchinson successfully completed the junior Great North Run in October last year raising around £ 110 for the LAM Trust, mainly from family and friends. Our congratulations and thanks to all involved.

## *4th Annual Meeting*

**3<sup>RD</sup> June 2000 at City Hospital,  
Nottingham**

The fourth annual meeting for LAM sufferers and their families will take place as detailed above in the Clinical Sciences building between 10.00 am and 4.00 p.m. It is an informal gathering of a range of people involved with LAM, patients, families, and medical staff. The meeting will include updates on research, funding, medical developments, the trust, and a report from the latest LAM symposium held in New York. Patients should have received a draft agenda and registration form during March, contact the team at city hospital if any further details or places are required.

## *News from Nottingham*

**Part 1 - General Developments**

*Anne Tattersfield*

Life is a little more peaceful now the millennium has come and gone and we are all back to work as usual. The LAM Trust has made significant progress on a number of fronts in the last few months. As many of you will know we now have a splendid web site— well done Claire and Ian Lauwerys – and thanks to Teresa Hewat for the new and very smart logo. Claire and Ian will give a demonstration of the web site at the meeting in June – particularly for those who have not yet embraced Tony Blair's internet revolution. The first edition of the LAM post looked very professional thanks to Joy Wadsworth and if anyone wants to write I'm sure Joy would like to hear from you. We

### **Inside**

- 1** Life with LAM
- 1** Fund-raising Fiona
- 1** 4th Annual Meeting
- 1** News from Nottingham
- 3** Health Foods
- 3** Me and My LAM
- 5** LAM Protocol
- 6** Who's who

have also noticed a big difference since Jan Johnson started to help with the LAM Trust and I'm sure it is a help to Jane and Brian Ward.

There have also been some developments with respect to our contacts with organisations outside the UK. Simon Johnson went to a meeting in Europe to discuss rare lung diseases and the group decided to set up the European Orphan Lung Disease Group(GOLD), with Simon being responsible for LAM. I have been asked to join the LAM Foundation Clinical Advisory Board in the United States. Jean-François Cordier who runs the Rare Disease Register in France is also joining so the links between the UK, the rest of Europe and the US will be very much stronger. Members of the board will meet at the American Thoracic Society Meeting in May so I will provide feedback in June. Obviously the more contact we have with the LAM Foundation and with European developments the better.

Also the British Thoracic Society is setting up a rare disease register which in the first instance will contain ten rare lung diseases including LAM. Quite how the LAM Trust will relate to the BTS register has not been sorted out yet but in essence they would want to support developments such as the LAM Trust and the LAM Register would continue to be based in Nottingham. Incidentally, Simon has now been appointed to a senior lecturer post in Nottingham which means that he will stay in Nottingham as a consultant but with more time for research than he has at the moment. Simon will tell you more about developments in research and we will be discussing these and other matters at the meeting in June.

We look forward to seeing you then.

## **Part 2 - The Trust**

*Jan Johnson*

Since taking on the post of LAM coordinator last summer things have changed a bit in the Johnson household, not only do we now have to fight for time on the PC but my e-mail in-box is fast approaching the size of Simons, seriously though, things do seem to have moved on considerably in the past 9 months. The new website is wonderful and has received much praise, likewise the new logo which looks great now that the stationary has been printed and gives us a much more professional image. We have also had some t-shirts and vests printed with the logo on the front, chiefly for our fundraisers to wear but they will be available at the meeting in June or directly from me if you can't make it to the meeting. I'm afraid we will have to charge £6 each for them to cover costs although this charge would be waived for fundraisers of course.

The LAM registry is coming on very well, about 80% of women with LAM in the UK responded to our request for information, almost all of whom have agreed to be on the database. Many thanks to all of you who took the time to complete the forms and to so many of you for agreeing to participate in research, it is a great help.

As I think most of you know I am also responsible for organising the LAM meeting this year, although I think that I may have caused some confusion by putting Jane Tallents name on the freepost return envelopes. For those of you who do not know Jane is Anne Tattersfield's secretary and very kindly agreed to be the forwarding point for my mail at City Hospital because I work mainly from home, Jane also deals with the cheques from LAM fundraisers

although this may change in the near future too. Anyway back to the LAM meeting, we are all looking forward to the day and to welcoming you to Nottingham whether you be an returnee or a new face like me. I am really looking forward to putting faces to all of those names that I have been typing into the computer over the past few months. Most of you have replied now and have sent in some interesting suggestions for what you would like to see on the agenda, we are working on this now and will be sending this out together with a map and a confirmation slip in early May.  
Hope to meet you in June.

### **Part 3 - Research**

*Simon Johnson*

Research into LAM continues at an ever increasing pace. In general the calibre of research improves all the time; largely due to the recruitment of scientists already working in areas related to LAM by the LAM Foundation. Last November I attended the LAM Foundation / National Institutes of Health LAM symposium in New York. The two day meeting, devoted exclusively to LAM, was attended by about 50 physicians and scientists from the USA, Europe, and Japan. Presentations from scientists working in genetics, biochemistry and cell biology complemented clinical studies of women with LAM. The main areas of interest surrounded the role of the tuberous sclerosis genes in LAM, trying to grow the smooth muscle cells of LAM in order to study their behaviour and studying what makes smooth muscle cells grow generally. I presented some of our research and it was very useful to have feedback from scientists working in related areas. I will be discussing some of the highlights at the meeting in June but for anyone who can't wait a summary is

available at the LAM Foundation web site ([www.lamtrust.co.uk](http://www.lamtrust.co.uk)).

As you will be hearing the LAM registry now has information upon the majority of women with LAM in the UK and with many people keen to take part in research this will be a great boost to our future research on LAM.  
Hope to see you at the meeting in June.

## *Health Foods ?*

'When I was in the States last time there was a LAM patient there who also follows a low fat diet and she had decided to become veggie and had increased the amount of soya or tofu that she was eating. She had had a serious deterioration in her health and the doctors thought that it may well be that the natural oestrogen in the soya was increasing the rate of acceleration of the disease and they strongly recommended that she cut the soya right out of her diet. Along the same lines a lot of the US patients take Chinese medicines and the doctors are not too happy about this either, as a lot of the herbs and plants also contain oestrogen.'

## *Me And My LAM*

*Theresa Hewat*

Our yearly meetings in Nottingham, have been a great source of information and comfort to me, but contact once a year is not enough to share feelings and emotions. Because this is such a rare condition, the isolation makes it so much harder to cope with.

About 18 years ago, I discovered that I was infertile. I cried and raged about it for a while, then formed an Infertility Group where, once a month, 10

women shared their despair and were able to comfort each other enormously. Happily, LAM has a newsletter and I hope this article will have some resonance with a few of you and that perhaps you will write something in the next issue.

I was diagnosed with LAM ten years ago (May 2000 is the terrifying anniversary).

I was hardly affected by it for the following 7 years, but latterly, and especially during the last year, my lung function seems to have deteriorated more rapidly. At an average peak-flow of 200, and with intermittent chest infections, at times I struggle to keep up normal family life.

However, I'm a stubborn person and I rarely make concessions to LAM. This sometimes means that I find myself in situations I can't cope with, trying to rush to Parents Evening at School, make the orthodontist appointment with my daughter, and, somewhere in between, cooking supper. Pride makes it hard for me to ask for help, but slowly I am learning that it's too much of a struggle to carry the logs in or take a basket of wet washing out to the garden. But I hate it.

I'm lucky to have, not only a very supportive and loving family, but a handful of very good women friends.

In this area also, I try not to let LAM alter my lifestyle. Unless I'm actually bed-bound, I'll go to every Book Group meeting, drinks or dinner party, movie trip or theatre evening, even day-trips to France.... but I notice that, increasingly, my concerned friends are trying to make life easier for me.

They will insist on driving when I know it's my turn, hunt out a lift in a shop so I don't have to struggle with the stairs, or tactfully offer to bring food to an event I'm hosting. Although I

appreciate their concern and they may well be right, I hate it.

I don't want the world outside to know about it either, I have to be desperate before I'll ask for help unloading my trolley in a supermarket or garden centre, I have to be completely cornered by flights of stairs and no lifts before I'll explain that I have 'breathing difficulties' and can't get up to the 4<sup>th</sup> floor..... and how daft do I look when there's a sudden cloudburst, the heavens open, everyone legs it to the nearest shelter, and I'm seen strolling at a very leisurely pace, getting drenched. Not being able to breathe properly is a terrifying experience. Each time I panic and lose my breath, for a second, I think I might die.

When I was going through a bad patch, but insisting on doing the weekly supermarket trip, my teenage daughter said that if she had LAM and the possibility of losing her breath in public, she would just not go out.

She thought I was being incredibly brave.

That cheered me up and I realised that all us LAM sufferers are being brave. Every time we push our fears to one side and do the things in life that are challenging, we are taking control and being tremendously courageous.

It may be taking up canoeing, cleaning the windows, or painting a wall; each time it feels like a victory against an unfair and seemingly implacable foe.

When I'm feeling a bit low about my condition, I think about the women I've met at the Nottingham meetings and feel comforted. Although I know none of you well, I feel a bond with you because, to some degree or another, you are going through the same things I am. No matter how supportive and caring friends and family are, they can never know how we feel.

So, keep on keeping on – and I hope to read about some of you in the next newsletter.

## *LAM Protocol*

**National Institute of Health (NIH),  
Bethesda, Maryland, USA**

*Lucy Falconer*

The Protocol was set up to collect data from as many LAM patients as possible over a 5-year period. This data is valuable for LAM research which will benefit all LAM patients, and individual patients can benefit from the expert advice available at NIH. The LAM team, headed by Dr Joel Moss, makes recommendations to patients' primary doctors and consultants; it does not treat or prescribe.

LAM volunteers are welcomed from all over the world. Everything provided at NIH is free of charge; including meals, accommodation, and transfer to and from the airport. To be accepted onto the programme, a doctor's referral letter, copy CT scans, x-rays, pulmonary function tests and tissue samples (if available) need to be sent to NIH beforehand. When accepted you can book your stay at your convenience, provided there is space available at the time you want.

What is it like at NIH? I found it very comfortable, friendly, busy and above all, fascinating. The tests are extremely thorough with results usually available to the patient by the next day, and the medical team are always willing to answer questions and discuss findings. The opportunity to talk to other LAM patients over a 4-day period is also very valuable.

The standard tests include: chest x-ray, bloods, 24-hour urine collection, pulmonary function test, CT scan of chest, abdomen and pelvis, bone density scan, MRI brain scan, EKG,

arterial blood gas, walking test, kidney ultrasound, detailed medical history and a medical examination. Extra tests may be ordered if there are additional concerns.

If you have a needle phobia or problems with flying, NIH is probably not for you. But if you wish to contribute to LAM research, and to find out more about the disease in general and your own health in particular, I would definitely recommend going. I will be happy to supply further details upon request.

## *Who's Who*

**Editor**

Joy Wadsworth  
01676 533157  
Wadsworth@netlineuk.net

**Contact Point**

Jane Ward  
0115 924 5052

**Medical team**

Professor Anne Tattersfield &  
Dr Simon Johnson  
Division of Respiratory Medicine  
City Hospital  
Nottingham  
0115 840 4772  
anne.tattersfield@nottingham.ac.uk

**LAM Register**

Jan Johnson  
c/o City Hospital,  
Address as above  
0115 840 4772

**Support register**

Theresa Hewat  
01225 865048

**Donations**

Jane Tallents  
(secretary to Prof. A. E. Tattersfield)  
Address as above.

**Web Site**

[www.lamtrust.co.uk](http://www.lamtrust.co.uk)

This newsletter has been produced on behalf of the British LAM trust. The aim is to provide information to existing and newly diagnosed sufferers of this rare condition. Any contributions by patients, medical staff, families and friends will be welcome, also suggestions for other areas we might cover. Items for the next edition to Joy by early September please.