

Life with LAM

Following the last issue of the newsletter we have received a number of accounts from LAM sufferers of their trials and tribulations with the condition, and we will print these over the next few issues, but please keep them coming, after all with 52 patients on the trust register that should last us about 9 years. We were delighted to see Alison Leslie at the meeting following her lung transplant and her account of this is included in this issue, we also include a contribution from Gillian Turner who is unable to attend the meetings due to her poor health, however she sends her regards and is delighted with the contact with other patients provided by LAMPost.

Congratulations

Our best wishes go to Alison Leslie who seems to be dominating this issue, she was created a MBE in the recent honours list..... may God bless her and all who sail in her.... or something like that.

Fundraising

As mentioned in the report of the annual meeting it is hoped to significantly increase the amount of money raised for the LAM Trust over the coming year. A significant portion of the meeting was given over to a discussion of this issue during the meeting and the following items emerged, some of which are covered in more detail in other sections :-

The best fund raisers are ourselves, that is the friends, family, colleagues of patients and the patients themselves.

Simple ideas can add up to a significant sum.

A nationally known patron would be an advantage when dealing with business organisations - it was agreed that the trust should approach Jennie Murray to fulfil this role.

Using national events e.g. the London marathon to raise money could bring in real benefits.

Some ideas to try at work :-

- ❖ raffles in the office
- ❖ 2 pence pieces in film boxes – capacity 50p (amounted to £700 recently!), or 5 pence pieces in Smarties tubes – capacity £5
- ❖ Bring and Buy cakes and plants
- ❖ Coffee mornings – recently raised £110

Other areas for exploration:-

- ❖ contacting a group called The Corrs – an Irish pop group, as the mother of the members had died recently from a ‘rare lung disease’.
- ❖ women’s sources. We should write to high profile women to see if they can help.
- ❖ women’s groups, e.g. Inner Circle
- ❖ a professional fundraiser
- ❖ skills auction
- ❖ gifts at petrol stations - it is often possible to exchange points for a cheque for your preferred charity rather than say a set of glassware.
- ❖ National Lottery
- ❖ Christmas cards
- ❖ selling advertising/hot link space on our web site

Christmas Cards

Please note that LAM Trust Christmas cards will be available this year at a cost of £3.50 (inc. P&P) per pack of 10 quality gloss finished cards with envelopes. All profits will go to the trust, contact Jan Johnson for details.

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2 *The London Marathon*

I am happy to say that we have five places for next year's London Marathon. We are looking for enthusiasts who would like a place and who are also confident of their ability both to complete the course and raise money for LAM. Since there are likely to be more than five people who wish to do this we are asking anyone who is interested to provide a very brief outline their proposed training programme and any relevant previous running experience, together with an outline of how they plan to raise the money and how much money they think they can raise. We know that people doing the London Marathon have raised at least £1000 each for other charities and sometimes over £2000. We hope to provide some sportswear gifts as incentives to runners who collect the most sponsorship and will announce further details in due course. Certainly, the person who raises the most money this year will have a guaranteed place for the 2002 London Marathon.

Runners who would like to run for LAM might also wish to apply for a place through the usual application system since, if they are successful, we would then have more than five people running for LAM. The closing date for the ballot is 20th October 2000. Please let me know if you need an application form or write to The London Marathon Limited, PO Box 1234, London SE1 8RZ.

It would be nice to decide who could have the five places reasonably soon so that applicants won't start to look elsewhere. Could you please ask anyone who is interested to drop me a line by 10th October please (c/o Respiratory Medicine, Clinical Sciences Building, City Hospital, Nottingham NG5 1PB, or e-mail: jan.johnson@nottingham.ac.uk). I have a draft advertisement which you could either adapt for use locally or we could send you a larger version if you wish.

Jan Johnson

Great North Run

Once again Fiona Hutchinson will be taking part in the 3 mile Great North Run this October. If you would like to sponsor her please contact Fiona via Marie Hutchinson for a sponsorship form.

4th Annual Meeting

A full report is included at the end of this issue, however we have included a synopsis here.

The meeting was attended by 40 patients, relatives and guests. The morning session included discussion of current developments, nationally and internationally, an update of research, finance and fund-raising and news about the Trust. In the afternoon there was a question and answer session and small group discussions.

Welcome and review of current developments – Anne Tattersfield

Anne mentioned the setting up of two organisations concerned with the study of rare lung conditions

- a European organisation GOLD (Group Orphan Lung Diseases)
- and a British version (BOLD)
- Simon Johnson will represent LAM within GOLD.

Hopefully the formation of these two new collaborative associations will speed the research on LAM and other rare lung disease.

Simon has also received a grant to study an enzyme associated with asthma which may also have relevance to patients with LAM.

There were two major items of interest from the recent meeting of the American Thoracic Society, firstly that data published at the meeting showed that the rate of decline of lung function in the early years of LAM can be significantly greater in those who smoke.... so if you want to do something for yourself about your disease then stop! Secondly, in patients with enlarged abdominal lymph glands, these glands could vary in size by 100% during the day, smaller in the morning - larger in the afternoon, so that changes in the size of these organs shown on CT scan could just be due to the time of day the scans were taken.

Research Update – Simon Johnson

International meetings

In November last year the LAM Foundation invited Simon to speak at the LAM Symposium in New York, about 50 scientists, physicians and members of the LAM Foundation attended. The LAM foundation contacts scientists working in related areas and will offer funding for work relevant to LAM. The fields of Tuberous Sclerosis genetics and smooth muscle biology are now producing very high calibre research. Simon also gave a talk on his research in LAM at the American Thoracic Society meeting in Toronto in April.

Recent research developments have focussed around possible chemical and genetic mechanisms for LAM, particularly growth factors, tissue destroying enzymes, and the genes that cause Tuberous sclerosis (TS). Genetic research has shown that whilst LAM patients do not have the abnormal TS genes throughout their DNA (and therefore can't pass it on to their children) these genes do appear in affected lung and kidney tissue. Thus LAM and TS are related but not the same disease.

LAM Trust

Jan Johnson now works for 6 hours a month for the LAM Trust. Her main role is the maintenance of the patient database to assist in research, liaison within the trust, and financial administration.

Fundraising

This will be covered in much more detail elsewhere in the newsletter, we currently raise around £10k per year and proposals were made at the meeting to try to significantly increase this in the future.

Producing the Newsletter

The newsletter will be sent out twice a year. Joy Wadsworth reminded us that we all write the newsletter with medical information provided by Simon. She asked for contributions for the next issue such as accounts of coping with LAM.

Setting up the web site – www.lamtrust.co.uk

Claire and Ian Lauwerys gave an expert demonstration of computer skills as they unfolded the stages of setting up the web site on screen. The cheapest host they could find was Way to the Web Ltd at an annual cost of £100 – which Ian and Claire have very kindly offered to cover.

Question and Answer Session

Low Fat Diet

This can be useful in controlling chylous effusions or fluid in the abdomen. It may also reduce the build up of chylous fluid in patients with blocked lymphatic ducts.

Exercise.

In general under exercise is more harmful than over exercise, its generally good to do regular gentle training, but check with your consultant first.

Availability of oxygen.

Oxygen is only really required when blood oxygen level start to fall and it may be helpful to take it initially at night if levels are lower during sleep.

Conclusion

The meeting was again a success for both 'old hands' and 'new faces' it was decided to try to set up a second set of meetings on an informal regional basis to try to allow other sufferers who cannot travel far to gain the benefit of these sessions. These would supplement the annual meeting which may be moved to later in June to avoid bank holiday weekend.

4 *Me and My LAM 1*

Gillian Turner

How many times have you heard it said that if you have good health then that is the most important thing in life? Before I was ill I often heard it, and although I didn't really agree I didn't argue.

As well as LAM I have cardiac tumours, pulmonary hypertension, asthma, osteoporosis, steroid myopathy, polyarthritis (because of the last two I can, even with the use of a walking aid, manage to walk only about three or four yards), diabetes and hypogammaglobulinaemia, i.e. my immune system doesn't work properly and I have to be topped up every three weeks with other people's - thank you blood donors - so that I don't have quite so many infections. I'm down to about three a month now. As well as enough drugs to stock a chemist, I'm also on oxygen for a minimum of sixteen hours a day. According to the received wisdom above I should be nigh on suicidal. I'm not. I'm not 'in denial' either. I deal with the practical aspects of what is wrong with me and then get on with enjoying life. There are a great many things that I can no longer do, but what is the point of complaining? There is nothing I can do about it, and I'd far rather spend my time doing things that are possible. From my wheelchair and with the help of a friend I am able to garden in pots and baskets. I can read, write and paint. I have friends who pop in every day to see if I need anything or for a chat, usually both. These days, if I hear someone quoting 'if you have your health . . . etc.,' I tell them that they are wrong. Health, good or bad, isn't really important. The most important thing in life is to have good, caring friends.

As for living with LAM (and the rest!), my prescription is this. Don't dwell on what you can't do; do what you can do. Ask for and accept help when you need it; explain why if you don't. You will feel down at times however positive your attitude; don't worry about it, everyone has spells like that, whatever their state of health. Whatever you do, don't let your illness take over your life. Deal with the practical side of it and then put it where it belongs, at the bottom of things to think about.

Dylan Thomas wrote 'Rage, rage against the dying of the light.' I think he was wrong too. Personally, I intend to use any energy I have not in being angry, but rather in making the most of what light I have left.

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Alison's Story

I was diagnosed with LAM in 1991, and by November 1998 my consultant at the Freeman hospital decided that my condition had deteriorated to the point where he would assess me with a view to a lung transplant.

After 3 days of tests it was decided that I was suitable, and my name was placed on the "active list".

Following 3 false alarms, I received a call at 2 a.m. on 19/01/2000 to say that a single lung was available for me.

I gathered my bag (which was already packed) and off we went to the hospital, by 4.30 a.m. I was in the operating theatre!

I was, of course, nervous and apprehensive on the way to the hospital, but I knew the routine by then, and I had also grown to know the transplant ward staff and the co-ordinators.

I had no fears of the operation, the staff were so encouraging and my condition had deteriorated so much that I was relieved that, after 14 months of waiting, it was going to happen at last.

The operation lasted 5 hours and went well. I spent the following 48 hrs in intensive care (of which I knew nothing as I was kept sedated) and was then transferred to a cubicle on the transplant ward itself. I had my own TV, video, phone, bathroom, and visiting was anytime. The care and attention was wonderful and within a couple of days I was able to take a shower and have a short pedal on an exercise bike (only a few days before I couldn't walk ten yards..).

I had been warned, however, to expect a possible rejection and sure enough I had a minor one at 1 week. I had been assured that this would be treatable and that treatment consisted of 3 one-hour courses of steroids, administered intravenously. I was confined to my room during this time for fear of infection, after this episode I picked up again and was discharged in 15 days.

It was wonderful to be home and even to walk up stairs without gasping for air was an unbelievable feeling.

Unfortunately, after four weeks, I again suffered a rejection and spent another 8 days in hospital.

Since then I have gradually improved and a biopsy at 3 months showed no rejection at all.

I started going on short walks, which at first were tiring because although I had a new lung my muscles were weak through lack of use.

My next milestone is the 6 month biopsy, and providing this is fine I am considering going back to work, but at the moment I take each day as it comes and appreciate the new life I have been given, all through someone who cared enough to carry a donor card.

I realise that a transplant is a major operation and that setbacks can occur but, in my experience, with a positive attitude and wonderful staff to care for me and answer my worries, I improved daily. I also know this from talking to other transplant patients who have all had different experiences but have got there eventually!

If anyone would like to know more, or simply like a chat please do not hesitate to contact me.

My very best wishes to you all

Alison Leslie

Who's Who

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Web Site

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 March 2001 please.