AUGUST 2023

LAMPost

LAM ACTION
Supporting women with Lymphangioleiomyomatosis

Super Cooper!

From the Editor's Desk

I'm really not sure if I can justifiably call this the 'Summer' edition of LAMPost, as the summer itself has been notably absent save for a few rare glimpses here and there! Nevertheless, I hope you have been managing to enjoy what meagre sunshine there has been and that you are all keeping well.

Not too much waffle from me this edition as I'm running a bit short on space (in the print version), but once again I am indebted to everyone who has contributed to this edition - please take a bow and know that your efforts are greatly appreciated!

We have lots of great articles for your reading pleasure, particularly regarding some absolutely wonderful fundraisers which have taken place since the last edition, and everyone at LAM Action sends their heartfelt thanks. If you have also held a fundraiser recently that is not featured here, then rest assured that we are incredibly grateful to all our fundraisers who are vital in allowing the charity to continue to function and meet its objectives.

Talking of fundraisers, good luck and a very big thank you to **Deborah Kamis-Murphy** who has organised a group of knitters and crocheters who will be selling their wares at a local fête to raise funds for LAM Action on 31st August between the hours of 11.00 am and 3.00 pm at The Christopher Pickering Lodge, Hessle Road, Hull. Any East Yorkshire based ladies with LAM who would like to pop down to offer their support would be more than welcome.

LAMPost will return in the winter, with a publication deadline of **December 5th**, please email any articles or other contributions to: **lampost@office.lamaction.org**.

Until then please enjoy what's left of the summer, keep safe and well, and very best wishes.

John

Scottish
Patient
Support
Group

Do you live in Scotland?

LAM Action is planning to set up a local group for women with LAM in Scotland. The idea is first to organise a café meet-up in Edinburgh this autumn. We would then alternate between Glasgow and Edinburgh venues for subsequent meetings. Depending on interest and where people live, we might also try to have interim Zoom meetings too.

If you are interested, please get in touch with our lovely LAM Action coordinator, Jill Pateman, on 07710 527636 or jill.pateman@office.lamaction.org. We look forward to seeing you!

Heather Taylor

We were very sad to hear from her husband Ralph that Heather Taylor died in June. Heather and Ralph were longstanding members and regular supporters of LAM Action, and some of you may have met them at past annual meetings. They lived in Doncaster. Our previous coordinator, Jan Johnson, describes Heather as "always immaculately presented", and was aware that in addition to LAM, Heather had fought breast cancer twice in recent years. Current coordinator Jill Pateman also knew Heather well, and commented on her raising awareness of LAM amongst her local breast cancer team. As Jill said, "I'm pretty sure that Heather was the reason that all the Breast Care Nurses that I used to work with for Breast Cancer Care in Doncaster knew about LAM".

Our condolences to Ralph and their family on their loss.

Heather and Ralph Taylor at the 2008 Annual Meeting

LAM Action’s 2023 Annual Meeting

On 10 June, LAM Action’s annual patient meeting was held online. Initially, we had hoped to meet in person, after three years of Covid disruption. However lingering Covid concerns, train strikes, and high accommodation and travel costs amid the cost-of-living crisis meant that many people were still reluctant to come to Nottingham. Of course, thanks to the professional expertise of trustee David Mercer and his team, we were still able to deliver the meeting online.

But while it is fantastic to be able to provide the meeting in this format, we are determined that next year’s meeting will take place in person. One of the biggest benefits of the meeting is the opportunity to meet and chat informally with other women with LAM, their friends and their families, and this camaraderie and these connections just can’t be replicated online.

Below, we summarise the meeting, in the order of the presentations. We encourage you to watch a recording here if you didn’t catch it live:

https://lamaction.org/meetings/watch-lam-actions-4th-virtual-meeting/

Prof. Simon Johnson – Medical Management of LAM in the UK

Whether your LAM diagnosis was decades ago or days ago, Simon's 30-minute talk is essential viewing. He began by stressing how management of LAM in the UK today is very personalised: "What I really want you to take away from the talk today is that LAM is a very variable problem, and I'll talk about how we try to personalise treatment of LAM to your particular version of the disease... We're getting better now at predicting what's going to happen to individual people and we understand that LAM is not the same for everyone."

There followed an informative talk on the different ways in which LAM affects people, their symptoms and problems, and the range of treatments that are available.

The final part of Simon's talk covered the LAM Centre. He introduced the newly expanded team: the four physicians, Drs Simon Johnson, Dominick Shaw, SyGiin Chong and Gauri Saini; the two specialist nurses, Hollie and Sharon; and the centre's administrator, Wendy. He also talked about their approach to delivering care, collaborations with relevant units and measurement of patient outcomes. Finally, he explained how patient data collected at the centre is informing medical management. Machine learning (artificial intelligence) has analysed 25 characteristics for each patient - such as age at presentation, presenting symptoms, and level of lung impairment – and identified three main clusters of patients. Work of this kind helps determine likely prognosis for individual patients and means that treatment can be personalised.

The talk was fascinating; both reassuring and hopeful. Many, many thanks to Simon and the entire LAM Centre team.

Dr Caroline Hill – Diet considerations for those with LAM

Registered dietician Dr Caroline Hill had prepared a talk about Nutrition and LAM. While tailored to women with LAM, most of what Caroline talked about would be of interest to a wider audience, for Caroline's main message for LAM patients is to *eat a healthy, balanced diet;* that is, try to maintain a healthy weight, keep bones strong and body mass lean, and ensure that you are taking in adequate vitamins and minerals. She also cautioned to avoid fad diets or unnecessary restrictions. For help about what constitutes healthy eating, Caroline talked through the **Eatwell Guide**, a UK Government publication which is readily available online, and gave us tips on how to make positive dietary changes.

Caroline then addressed the specific LAM question about whether women with LAM should avoid foods containing phytoestrogens – also known as plant oestrogens – such as soy products like tofu and soy milk. Oestrogen is implicated in the progression of LAM, but there is no hard evidence on the impact of eating plant oestrogens on LAM. Therefore, Caroline echoed the same message that Simon has been delivering for years: consider eating these foods in moderation, rather than avoiding completely.

This may be of particular interest to women going through the menopause, as plant oestrogens are thought to help reduce some symptoms of menopause, such as hot flushes. Continuing this theme, Caroline gave some other food tips to help with menopause symptoms. She concluded her talk with advice on diet and supplements. If you are interested in getting more information on this subject, Caroline provided details on the final slide of her talk, and very kindly invited anyone with further questions to get in touch with her.

Personal stories of living with LAM

One feature of our annual meetings that everyone especially appreciates is meeting and hearing from other women with LAM. This year, we had short talks from three different women about their experience of being diagnosed with and living with LAM. Many thanks to Lisa, Jo and Tess for opening up and sharing their very personal stories with us. They are all hugely inspirational.

Dr Debbie Clements – New ways of treating LAM

Debbie is a scientific researcher who has been working on LAM in Nottingham for over two decades now, largely funded by LAM Action. In this talk, she explained some of her current work into potential new ways of treating LAM. Clearly, the drug rapamycin, also known as sirolimus, is a very effective treatment for many women with LAM, slowing or even stopping progression of the disease. However, there are some women for whom the drug is not so effective. Debbie told us about her investigations into why this might be, and how that might lead to alternative therapies for treating LAM patients. She also talked us through how "drug repurposing" – taking an existing drug that has already been approved to treat one condition and using it to treat another condition - might be particularly useful in this quest. Tests being done by Debbie and the team have identified potential drug candidates, and subsequent work is being done in the lab to test the effect of these drugs on LAM cells, both alone in different strengths, in combination with rapamycin and in combination with each other. Therefore, there is potential for this work to lead to new, effective ways of treating LAM for all patients.

This work uses tissue samples donated by LAM patients and Debbie thanked everyone who has contributed tissue for research, taken when they have been undergoing surgery.

Dr Karen Morton – Let's talk about the menopause

Dr Karen Morton is a consultant obstetrician and gynaecologist. She began with the basics: explaining women's reproductive systems, before addressing the stages, phases and management options of menopause. The age at which menopause occurs varies greatly but tends to be in a woman's late 40s/early 50s. The extent and type of symptoms can also vary greatly. For women with and without LAM alike, symptoms can be reduced by adjustments to lifestyle and nutrition: exercise, maintaining a healthy weight and eating a balanced diet. Pelvic floor exercises are important. Use of an Intra-uterine device such as a Mirena can be enormously helpful for perimenopausal women, reducing blood loss and alleviating other symptoms. (Mirenas can be used by women with LAM.)

The talk – and questions – then focused on the particular aspects of menopause pertinent to women with LAM:

- After menopause, bone mass declines, and this is a particular problem for women with LAM, who are known to be at higher risk of osteoporosis. A calcium-rich diet and load-bearing exercise can help.
- Historically, LAM patients have been advised to avoid HRT (hormone replacement therapy) because it contains oestrogen, a hormone thought to affect LAM adversely. Therefore Dr Morton talked through a number of drugs which can be used to treat menopause symptoms which do not contain oestrogen.
- According to Prof. Johnson, it is now becoming a little more common for LAM patients to be prescribed HRT; if someone has mild LAM but severe menopause symptoms, then there may be a case for prescribing low-dose HRT, as long as lung function is carefully monitored. Dr Morton confirmed that there is more flexibility in HRT dosing now, with products that can be provided in spray, gel and patch formats, which allow the amount of the drug to be minimised.
- Dr Morton also stressed the importance of keeping the vagina and bladder healthy. She believes that some of the oestrogen creams or pessaries which are applied directly into the vagina contain such minute doses of oestrogen that they could be used safely by LAM patients as a “local nutrient”.

The Lucy Falconer Talk by Dr Vera Krymskaya – LAM Research: Past, Present and Future

We were delighted to have Dr Vera Krymskaya update us on LAM research in the US. Like her UK counterparts, she has dedicated much of her working life to researching LAM in the lab. Vera is currently Vice-Chair and Interim Scientific

Director of the LAM Foundation in the US, and she joined us from Philadelphia, immediately after participating in a cycling event raising money for LAM.

As the title of her talk suggested, Vera began by recalling some of the history behind LAM research and two key discoveries: the identification of the role of the TSC2 gene in LAM, and the evidence that mTOR inhibitor drugs such as rapamycin target and slow the abnormal cell growth in LAM. But while rapamycin is approved as a treatment for LAM patients, it is not a cure, so currently labs around the world are looking at alternative potential therapies. One approach is to find a drug that might kill LAM cells, although if something is toxic enough to kill LAM cells, it may also be too toxic for patients. The growing field of immunotherapy offers promise too in the medium term; LAM cells appear to evade the immune system, but immune responses of individual patients vary, so this is another area being investigated. Finally, new technology is allowing more detailed analysis of lungs and the identification of different cell types, which in turn may allow investigation of how LAM cells talk to other cell types and point to further therapies.

For the future, Vera laid out two key questions: why does LAM affect only women, and how can we prevent lung destruction and restore lung function in LAM? The session then ended with a joint Q&A with both Vera and Simon. One question asked the extent to which their two research teams worked together, and it is clear that there has been and continues to be very close cooperation.

For LAM patients, seeing these two LAM leaders speak with so much passion and enthusiasm about their work was incredibly uplifting. It was also humbling, as it demonstrated how lucky we are to have Simon, Vera, Debbie and their colleagues working so hard on our behalf. Heartfelt thanks to them for their presentations, and to the other speakers and presenters for imparting so much valuable information, and for giving us that most precious of things, hope.

Gill Hollis

Sponsored Walk Along the West Mendip Way

On 9th and 10th August this year, my sister Sandra Bull and I undertook the challenge to walk the 30 miles stretch of the West Mendip Way taking us from Uphill on the west coast near Weston-super-Mare to Wells, the smallest city in England via the Mendip hills in Somerset.

The route took us via Crooks Peak and the famous Cheddar Gorge with lots of ups and downs along the way. We chose the right couple of days, after the wet July and August we have had, we had two glorious days of sunshine! The views were amazing, and although challenging, we thoroughly enjoyed it!

Although 30 miles over 2 days doesn't sound far or much of a challenge it was very hilly, but also, we both suffer from different restrictive conditions. Sandra was diagnosed with AS (Ankylosing spondylitis) when she was 21. A type of arthritis in the spine, causing inflammation and gradual fusing of the vertebrae. Symptoms include pain and stiffness in the lower back and hips leading to immobility. NASS, her chosen charity has supported her with hydrotherapy, ongoing social support, and exercises to keep everything moving for longer. I really don't know how she does what she does, as she works so hard, full time as Dean of Study at Weston College!

My chosen charity was LAM Action. I was diagnosed with LAM quite by accident when I had Sepsis. Not knowing why my body was in shock when I was admitted to hospital, they did a body scan which is when they noticed my lungs were 50% full of cysts! After ruling out lung cancer (I had never smoked), and finding benign tumours in my abdomen, they confirmed it to be Lymphangioleiomyomatosis. Not only had I never heard of this condition, but I couldn't even pronounce it or spell it!! The surgeon, having only ever seen one case before in his career, informed me that my prognosis was 5–10 years, which as you can imagine came as quite a shock! Since then, I was referred to Nottingham to see Prof. Simon Johnson, and was told the prognosis was much better than that. I am now on rapamycin/sirolimus to prevent my body producing more cysts. I have now been on this drug for 3 years.

It did take me a while to 'get my head around' this condition and found I suffered from breathing difficulties to begin with, feeling like an elephant was sat on my chest at times. I believe this was kind of panic attacks now, rather than the LAM, as although I do get tight chested from time to time, it's not as bad. I do find exercise limiting when going up hills or steps, but I am fine on the flat or downhill. In fact, during our walk, it was the side effects of Sepsis in my ankle that caused me the most discomfort!

Stunning views along the way

Proud mum Rosemary Tucker

Tired and weary

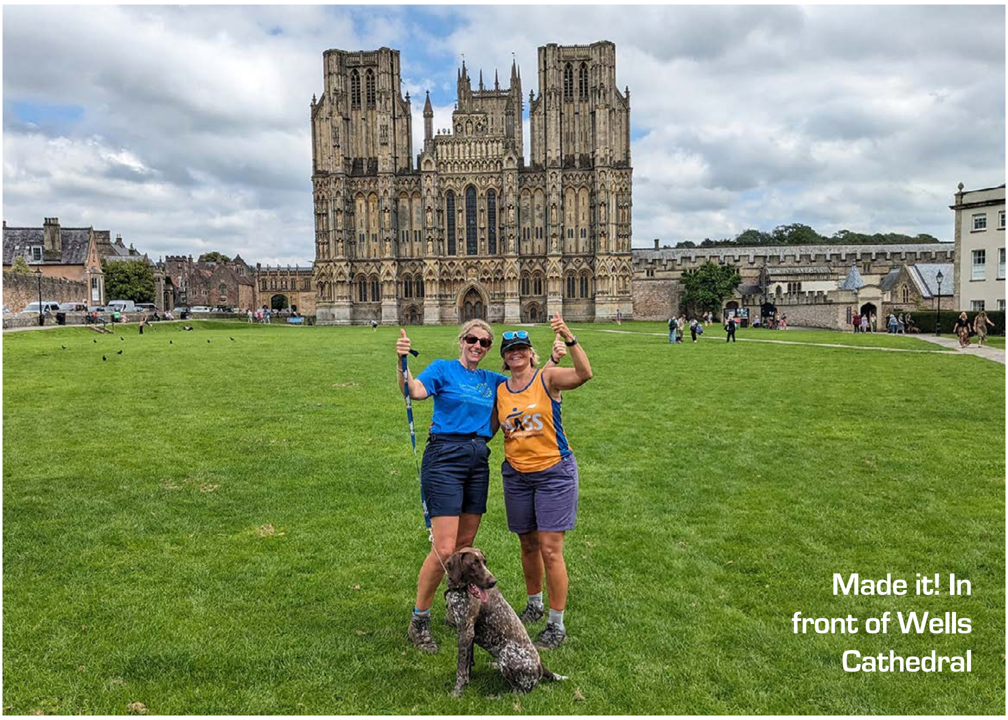
Between us, we managed to raise £1528, which was £764 when split between the two charities, and with gift aid comes to over £900 each! So well worth the effort, and I hope this will make a difference to everyone suffering from LAM.

We aim to do more fundraising in the future but will give our friends and relatives a break from pestering them for money for the time being!

Thank you to everyone who sponsored us and for the support we received.

Lucy Edmunds

Editor's note – If you would like more information about the West Mendip Way go to:
https://www.mendiphillsaonb.org.uk/walks/the-mendip-way/



Made it! In front of Wells Cathedral

A well deserved ice cream with Lucy's husband Simon

Wonderful Friends and Family

A Story of Hope!

It's mid-April 2023 and we've just enjoyed a fantastic meal at The Chester Grosvenor hotel in celebration of Erica's 50th birthday. There were savoury treats and cakes the likes of which we'd never seen, let alone tasted before, all washed down with something fizzy and very alcoholic. The afternoon tea was a lovely occasion surrounded by friends and family in amazing surroundings with fantastic culinary delights.

I can hear many of the readers asking why this is such a significant event. The significance comes from the fact that Erica was diagnosed with Lymphangioleiomyomatosis (LAM) at the age of 30 and at that time, given the knowledge that was available, she was given a life expectancy of 5 to 10 years. So, in all probability, we shouldn't have been celebrating her birthday this year!

We were just a normal couple that were enjoying life!! Active holidays abroad, career focussed, very proud new house owners and planning a wedding! Little did we know what we would have to face!

Erica suffered a series of spontaneous lung collapses over a 2-3 year period in the early 2000's, during which we were told that this was normal for 'young, tall, slim, athletic men'. For the record, Erica does not fit that profile!! But nobody seemed to be unduly concerned so we carried on in blissful ignorance.

A change of hospital to Chester, a biopsy and a diagnosis. Devastated that the positive diagnosis for LAM was given in the week of Erica's 30th birthday, a little over 6 months following our wedding and shortly after buying our first home together. A time when we should have been celebrating and looking to the future, instead all we had were questions.

- *What does this mean?*
- *What is the outlook?*
- *What was the treatment? Everything is treatable, right?*
- *How will it affect our lives?*
- *Above all, Why Erica?*
- *No-one could answer and Google was not our friend!*

We read stories of fast decline in lung function and transplants that were not wholly successful. Stories and accounts of how there were hypotheses on the mechanism by which this condition was ruining women's lives in their 60-70's but no real evidence to support them due to the lack of 'candidates'.

- *How did Erica fit this profile of women in their more senior years?*
- *What does it mean to be diagnosed so early?*
- *How would this affect the outlook?*

Our Consultant in Chester decided that a referral was in order to a specialist in the condition. We were referred to Wythenshaw, Manchester to see a Lung Consultant who had seen 4 ladies with LAM! This made him an expert in our eyes!! We should have felt reassured at this point, however more devastating news was to follow.

Erica's condition was also affecting her kidney with a very large angiomyolipoma (AML) being discovered that almost entirely enveloped one of her kidneys. On a positive note, Erica drew great attention within the hospital network due to the rarity of the disease, her age, and the size of the AML. We were comforted in the knowledge that we were getting the best treatment, but we still had so many questions.

- *How long has she had LAM?*
- *What were the implications of also having a large AML?*
- *Who would be able to co-ordinate the treatment of 2 very serious conditions?*
- *Why had Erica been chosen to be so unfortunate?*

There were still so many questions that lay unanswered, so few women from whom data could be collected, so little exposure for the condition and an apparent lack of co-ordinated research (at that time). We were probably 2 years into our journey at this stage and were feeling brave enough to interrogate Google again!

Erica enjoying sweet treats!

Eureka!!!!! We stumbled upon the now Professor Simon Johnson and the Team in Nottingham

Although Simon is now a key figure in the LAM world, back in the early 2000's meeting with Simon was all a little more clandestine! Grabbing consulting rooms on the fly, squeezing in lung function tests and trying to collate data based on the 80-100 subjects that had the pleasure of being labelled a 'Lammie'. Simon was connected to consultants that could help with the AML and other symptoms that are associated with LAM and this brought a renewed sense of security that someone understood.

But we had arrived! We were being looked after by the most pre-eminent Consultant for the condition in the UK, Europe and globally. We felt secure that we were being cared for by someone that was at the cutting edge of research, drugs trials and global collaboration. If ever there was a chance of contributing positively towards the greater fight, it was with Simon and the team. The more people that were referred to Simon, the greater the sample from which to gather data and get meaningful results from any trials that were carried out. I believe there are now in the region of 400 identified sufferers in the UK and the condition is now recognised in many more regions globally. Erica, along with many other 'Lammies' has taken part in trials for Simon that has brought about the common use of sirolimus which has been a gamechanger for the LAM community, well done Team LAM!!

As you will be aware if you have visited the Nottingham facility, the condition is now 'officially recognised' which has led to funding that has enabled a dedicated centre within the hospital and all the lovely staff that are associated with it. We visit Simon at least once a year in Nottingham. It's a chance to hear the latest updates, talk through any health changes and to carry out a rigorous Lung Function Test. This last point is more significant than it sounds as it's a litmus test of what's going on with Erica's physiology, but it also provides valuable data that can be processed by Simon and the team.

We view Erica's outcome as a success!

We were devastated by the diagnosis and some of the decisions and limitations that have been enforced upon us by the condition. We have had some very stressful times and been to some very deep lows. But Erica has refused to let her condition define her. She chooses to work part-time in a semi-physical job for her own mental well-being and walks several times daily with her sidekick Gryff, our miniature Schnauzer.

She's now 20 years post-diagnosis and she continues to hold her own as far as lung function is concerned, it's not typical for a healthy person of her age but her rate of decline is moderate. Her AML is very well monitored as it is of great interest to the Consultants due to its size, complexity and the fact that Erica is currently taking Sirolimus. Erica's AML is currently dormant. It would be fair to say that Erica's life is not LAM-affected currently. We realise she is one of the lucky ones!


Erica and Gryff

All the way through this article I have used the term 'we'. Although Erica has the condition, we have tackled this together throughout, we have attended all appointments together, we've been through the highs and lows together. There is only one part of our Team that can truly face the troubled road ahead, I get to watch from the sidelines and be the best supporting act that I can be. Our strength has come from each other, and we now look forwards to a life of relative normality together.

Learnings

- *LAM can be devastating and can be the definition of your life*
- *The lack of knowledge can be isolating, leading to heightened anxiety and depression*
- *There is now a wealth of knowledge out there, but be careful where you look!*
- *Start here* ***www.lamaction.org***
- *As the detection rates improve, the earlier people can be diagnosed and treated. This leads to a greater data pool and results that are more representative of the LAM population, not just more senior ladies that are in the Autumn of their condition*
- *Engage with The LAM Centre, be part of the solution!!*

Kevin Brooks

The Benefits of Tai Chi

Exercise is a very personal thing, and it can take time to find something that is maintainable. Roz Bushman has kindly written the following article detailing her very positive experiences with Tai Chi and Qi Gong.

In the past, I've had stints of going to the gym and joining other exercise programmes including a dismal attempt to do 'couch to 5k' – I physically dislike jogging up and down so I've no idea why I thought it would be a good idea. I've always enjoyed walking - you can set your own pace, do what you can do and going for a walk is good thinking time.

Then, in 2019, quite by chance, I joined a local Tai Chi & Qi Gong beginners' class. I'm still there, and still a beginner, but that seems to be how Tai Chi works – you are always learning something new and fascinating. Qi Gong is a pillar of Tai Chi and simply means breath work.

I'm struck by how beneficial these exercises are for Lammies. There is no pressure to keep up with anyone else; no agitated fast workouts making you feel you're about to explode. Exercise sequences are generally slow and controlled with much stretching and working of muscles – there are some quick movements, but these are generally balanced with slower ones.

I find Tai Chi & Qi Gong develop balance and core strength and, as they are done in an upright pose, do not require contorting the body in ways which I have found uncomfortable in other exercises such as putting pressure on the chest area. That said, you can do many of the exercises sitting or lying down when health requires that and there are members of my class who are seated.

The breath work is invaluable and an opportunity to explore how breathing works with movement, and generally calm down. It is sociable – doing a sequence of moves with other people in harmony are lovely moments – and you can practice what you learn at home, or outside, in your own time and you don't need any equipment or a particular space.

Tai Chi also works well when received online if you are housebound or unable to travel – as we found out in lockdown - and it seems that many teachers are now set up to offer classes online as well as in person. My classes are delivered by an academy which has several branches in the London area, but I believe from conducting a quick search that there are many Tai Chi & Qi Gong providers around the country.

Roz Bushman

2023 Christmas Cards

While you are probably not even thinking about Christmas yet, here is certainly nothing like planning ahead, and we have already ordered our Christmas Cards for this year, which again come in 5 beautiful designs.

The cards won't be arriving at LAM Action HQ until the end of October, so this is just a sneak preview, and we will be launching them along with the order form later this year so please keep your eyes peeled on our Facebook pages and your email inboxes come November!


Rachel Stinton, Paul Thomas & Mike Astley


Team Johnson: Prof. Simon Johnson, Naomi Johnson, Oscar Mahoney & Alex Slater

London Marathon & Ride London 2023

One of the most rewarding tasks as a LAM Action Trustee is being at the finish of the London Marathon and Ride London to meet the runners and cyclists who have been fundraising for the charity. Each one of them has their own story to tell about the event and though they may ache in different places they are united by their beaming smiles and sense of elation at what they have achieved.

THE LONDON MARATHON took place in April this year and these are the LAM Action runners who took part along with their comments after they finished:

Rachel Stinton lives in Leamington Spa and is a friend of LAM patient, Helen Sabin. Rachel said "The atmosphere was incredible and kept me motivated.

It was so good to see Kelly and David from LAM Action at the end and get the team photo. I am so pleased so have raised more money for LAM, and hope to do more fundraising for you in the future."

Chrissie Mills is a Clinical Project Manager at Papworth Hospital. Chrissie had previously completed a few 10km events and a half marathon and ran because one of her closest friends was diagnosed with LAM. After the event she wrote "If there is anything else I can do to help please do let me know. I have worked in clinical research now for over 15 years, I am happy to support any ongoing projects you have. Or if you need lay representation on your steering groups I would be more than happy to help."

Andy Judge is a Criminal Barrister who works and lives in London. He took up running 4 years ago and he ran his first London Marathon in October 2022 for LAM Action then did it again in April. "I have really enjoyed the process and if you will have me again, I would be happy to run next year. "

Nick Culley will be known to many as the technical wizard behind our Virtual Annual meetings. "The marathon renewed my belief in London…it was terrible weather, but I was amazed at how many people came out. It was an unbelievable experience and I probably could be convinced to do it again."

Mike Astley, a property accountant who lives in Knebworth, ran for LAM Action because of his sister in law, Caroline, who has LAM. "Having entered the ballot for the London Marathon unsuccessfully for the last 7 years and run the Virtual London Marathon last year around the lanes and cycle paths of Knebworth, Woolmer Green, Stevenage and Watton, I knew I had to run the real thing (yes, I know, before I'm too old!!) and it happened this year for LAM Action."

Paul Thomas from near Kidderminster is a friend of LAM Action's chair, Leanne Lillywhite-Sutton. "It was my pleasure to run for LAM Action. I'm so pleased to have raised more than £2000. It was important for me to run for a charity that I believe in, knowing Leanne makes it all a bit closer to home. I'd love to run for you again in the future."

Rick Nagle is an IT Project Manager who lives in the Netherlands, with his wife and young daughter. He's run 20 half-marathons, 3 Rotterdam Marathons and 3 New York City Marathons but this was his first time in London. "The London Marathon was an incredible experience, and I'm thrilled to have had the opportunity to participate and raise funds for LAM Action. I'm really happy that the money raised will go towards such an important cause. Knowing that my efforts will contribute to research and potentially help find a cure for LAM is incredibly rewarding."

Chrissie Mills

Andy Judge

Rick Nagle & Nick Culley

RIDE LONDON, the last big fundraiser of the year, took place on 28th May. LAM Action had 9 riders participating in this 100 mile cycle through Essex which finished on Tower Bridge.

We are very grateful to **Professor Simon Johnson** and his daughter, **Naomi** who took to their bikes with 2 friends – **Oscar Mahoney** and **Alex Slater** and formed 'Team Johnson'. After finishing Simon said "There was some trepidation beforehand, but it was a beautiful sunny day and I rode round with my daughter and I think we could have gone a bit faster actually… it was a very feel good event."
https://2023ridelondon.enthuse.com/pf/simon-johnson

Other members of LAM Action's Ride London Team were **Andrew Barham**, who completed the 60-mile ride and

Simon Fairbrother – a friend of LAM Action Trustee Sally Merritt-Collins. Simon is also taking part in the Royal Parks Half Marathon in October to continue his fundraising for LAM Action
https://www.justgiving.com/fundraising/simon-fairbrother3

Joining them on the road were two ladies with LAM – LAM Action Trustee, **Jo Pisani** and **Lisa Cooper**, who is newly diagnosed and cycled with her fiancé **Kev Jones**. Lisa was not satisfied with cycling 100 miles - she and Kev went on to ride from London to Paris in July. "4 days of cycling, covering 338 miles, 13.2k feet of climbing and 25 hours sat on the saddle. What an incredible journey it's been – all to raise money for LAM Action." Lisa's fundraising page is:
https://www.justgiving.com/fundraising/lisacooperlamaction


Andrew Barham


Jo Pisani


Simon Fairbrother


Lisa Cooper & Kev Jones

A big thank you to all the runners and riders for the hours they put into training, fundraising and the events themselves. Their efforts were worthwhile because in total the marathon runners raised over £13,000 and Ride London over £9,500. That money will go into research into LAM and support for the LAM community in the UK.

If you know of anyone – family, friends or colleagues - who would like to take part in future events please contact **david.mercer@office.lamaction.org**

That first small step can make a big difference to LAM Action.

David Mercer

Pedalling all the way to Paris

In July, Lisa Cooper set off on a cycling adventure with her fiancé Kev Jones to cycle all the way from London to Paris to raise funds for LAM Action. A towering achievement and just get an Eiffel of the amazing pictures they took along the way!

In June 2022, following a swim in the sea, I was taken into hospital after suffering a Pulmonary Oedema (cold water shock). Having received the all clear from the effects of this, a CT scan showed I had multiple cysts over both my lungs. Following further tests and scans, it was confirmed in July LAM. In August 2022, I suffered my first Pneumothorax and ended up having a double Pleurodesis.

Following the operation my surgeon had me cycling on a static bike within 24 hours... however, I already had a love of cycling, so I was more than happy to hop on and do all that I could to ensure the surgery was a success.

During my recovery, I wanted to set myself a goal to ensure I stayed as active as possible and one that would allow me to raise money for LAM Action.

Following a discussion with Professor Johnson, I decided to enter Ride London to raise money, however that wasn't enough, so I decided to use that as a warmup to cycle from London to Paris!

What an epic journey that was. Over 4 days, I cycled from

London to Paris, passing some beautiful towns (Dunkirk, Cambrai & Soissons) covering 338 miles, climbing 13,200 feet with 25 hours sat in the saddle.

The first day was the most challenging, due to it raining for the first 30 miles (not the best start), but also due to the hills, which felt like Mount Everest at the time! However, the rest of the time, the sun was shining all day long.

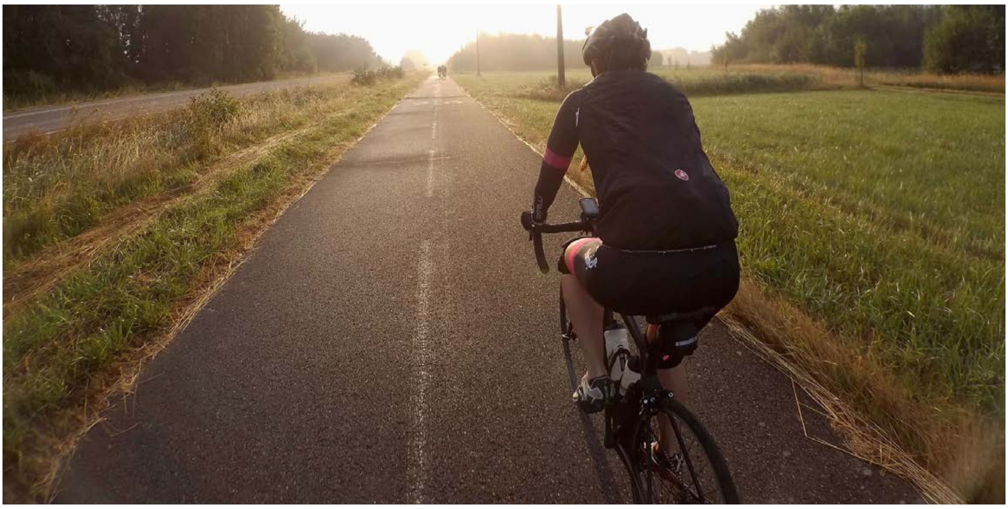
The final day was just amazing, knowing I was cycling into Paris at the end of the ride just seemed crazy, still now I can't believe it… I cycled to Paris!

Cycling around the Arc De Triomphe was an iconic moment, let alone dangerous, but when we got to the Eiffel Tower, well, I can't describe it, I'm actually tearing up just thinking about it, let's say I was absolutely buzzing!

Following my diagnosis & operations I didn't think I would be able to carry on doing what I loved, cycling is a big part of mine & my fiancé's lives and we often venture out at the weekends or take holidays to cycle, so completing this achievement gave me the hope I can carry on.

But by far the biggest achievement was raising money for LAM Action. With the generosity of friends, family, fellow LAM ladies & even people I didn't know, to which I THANK YOU all from the bottom of my heart, I managed to raise £3,684 for LAM Action, the absolute icing on the cake to the best journey… but I won't stop there!

Lisa Cooper




Welcome to
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The next edition of LAMPost will be out in winter 2023 with a deadline for submissions of **December 5th** - thank you!

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LAM ACTION
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