

DECEMBER 2024

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Hat Trick Hero

From the Editor's Desk



Are you hanging up your stocking on the wall? Here at LAMPost HQ we are looking forward to a bit of rest and relaxation over the Christmas period after yet another very busy yet hugely successful year for the charity, and we trust that you will also be able to have a peaceful and restful time with your loved ones. A very big thank you to everyone who has supported us this year!

Just a week ago we were really struggling for articles, and I am very grateful to those who contributed to this edition, which enabled us to have something to publish. Please have a think about whether you might be able to write something for the next edition, without your articles to keep us going, there might not be a newsletter for all our readers to enjoy!

With so many great fundraisers for us this year, we thought it would be useful to give an update on where your fundraising money and donations go. You can read about this on page 4 and it is certainly an interesting and eye-opening piece which underlines just how vital your efforts are to keeping the research going and you can rest assured that not a single penny is wasted when it comes to funding the fantastic team in Nottingham.

We hope that everybody now has the date of the 2025 annual meeting firmly in their diaries, but if not, please make a note that it will take place on **Saturday June 7th**. Once again we will be taking the meeting on tour, returning to Watford, which was the venue of a very successful meeting before COVID came along and we all got locked down. Watford was chosen due to its

accessibility, there is ample parking very close to the hotel, and the town itself sits on two major motorways and fast rail connections. We hope to see you there!

Please also make a note to complete the LAM Action survey which will go live on **January 15th**, please see details on page 8, and big thanks to Sally and Adam for all their hard work on it.

LAMPost will return in the Spring, with a publication deadline of **April 12**, please email any articles or other contributions to:

lampost@office.lamaction.org.

Until then have yourselves a merry little Christmas, wherever you may be, best wishes,

John

Season's Greetings

Best wishes for the festive season and for a happy and healthy new year from everyone at LAM Action



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Your Donations At Work

Most of the money that you raise for LAM Action goes toward research involving LAM. Research in a laboratory is an expensive business, with high costs driven by the requirement for specialised equipment and reagents. Below is an outline of the direct costs involved in bench research.

A standard Lab Researcher's salary including costs (per annum)	£48,121
A Lab Technician's salary (per annum)	£40,490
Access cost (lab fees for the Biodiscovery Institute at Nottingham University where we work, per annum)	£2,640
One antibody to detect a protein in lung tissue	£400
Kit to detect a protein in a patient's blood	£600
RNA sequencing, to detect multiple gene expression in 20 samples	£10,000
Spatial transcriptomics – this is a new technique to look at gene expression across tissue such as lung samples (not including cost of instrument)	£30,000

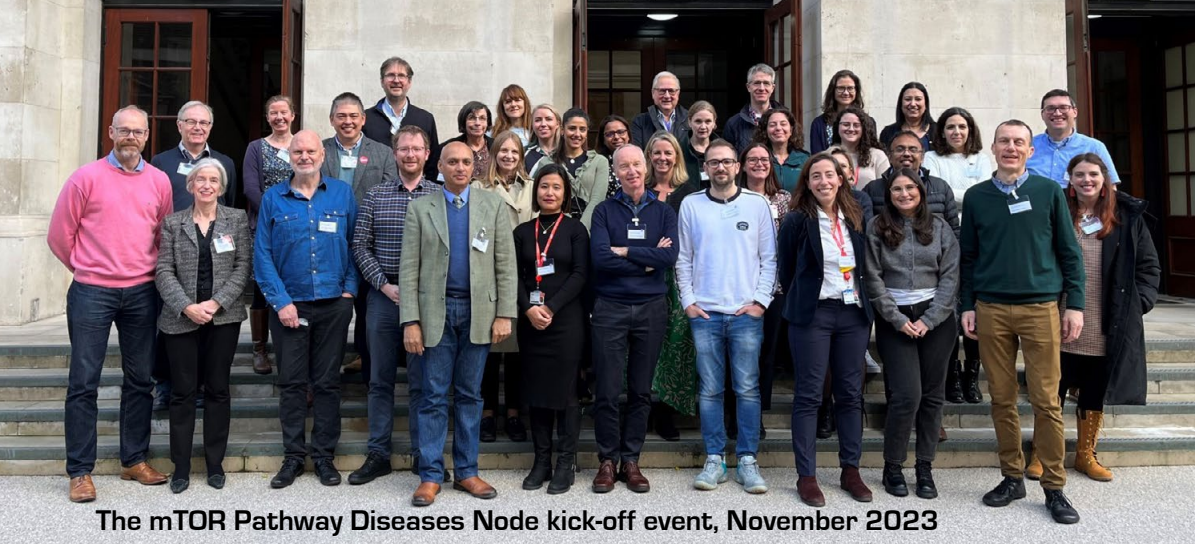
As a rule of thumb, it costs around **£20,000** per year to perform a standard laboratory research project, not including the researcher's salary, and if the project involves advanced gene expression work, then it costs even more.

Prof. Simon Johnson

Back on the Road Again!

The 2025 LAM Action Annual Meeting will be held at the Leonardo Hotel in Watford on Saturday June 7th - we look forward to seeing you there!





The mTOR Pathway Diseases Node kick-off event, November 2023

mTOR Pathway Diseases Node

More UK Research into LAM! In July 2023, the Rare Disease Research UK Platform was launched, following a £14 million investment from the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR).

The funding has been split amongst eleven “nodes”, each of which specialises in a particular area. One of these is the mTOR Pathway Diseases node, which unites 14 rare individual mTOR pathway diseases as a single group. The aim of its research is to improve the diagnosis, treatment and clinical outcomes for mTOR pathway disease patients. Both LAM and TSC are diseases involving the mTOR pathway and are represented in this node.

Prof Simon Johnson and LAM Action trustee Jo Pisani have been involved since its launch. You can read more about the mTOR Pathway Disease Node at <https://rd-research.org.uk/node/mtor-pathway-diseases/>.

Earlier this month, LAM patient Clare Lyon attended a PPIE (Patient and Public Involvement & Engagement) workshop on behalf of LAM Action. Many thanks to Clare for participating and writing the following report.

“I attended a PPIE workshop on 5 December at King’s College London, with delegates from other charity support groups, advisory panel members, researchers, clinicians and artists.

At the workshop, they gave us an update of the research that is underway so far, mainly in TSC, working on disease tissue and control tissue, comparing protein differences between the 2 groups, to gain new insight into the processes affected. The node has begun with TSC as there are larger numbers of patients (roughly 10,000) in the UK, compared with much smaller numbers of the other diseases.

They have also begun a patient registry, a database of mTOR pathway diseases. The initial focus has again been on TSC, with the aim to have a registry of all patients with mTOR pathway diseases by the end of 2025. They are currently working with the NHS NDRS (National Disease Registration Service) to pull data already held within the NHS, and they are contacting clinicians who are known to look after mTOR pathway disease patients across the UK to gather all patient data. Data analysis aims to build a clearer picture of mTOR diseases and improve diagnosis.

During lunch we made a paper model of the mTOR pathway, produced by a company called Origami Organelles. It was an excellent way to visually understand where in the pathway problems occur causing disease. It was very engaging and made a very complex process understandable to a lay audience.

We then contributed lived experiences to help the team start on an mTOR pathway node handbook, which they want to produce to make the work of the node accessible to a wide audience. We discussed different methods of communication, so the handbook was inclusive for any patient or member of the public.

We also had a break-out discussion to explore the similarities of the lived experience of people with the different mTOR pathway diseases. Isolation, uncertainty, frustration in diagnosis delay, difficulty in finding the right expert professional, lack of curative treatment options and mental health challenges were all identified as common themes.

Finally, each patient group represented then spoke briefly about the function and aims of their group/charity. The node would like each group to lead a session in the future. It was very encouraging to be involved in this new collaboration which will increase UK research into LAM and should ultimately benefit patients.”

Gill Hollis & Clare Lyon

Please tell us what you think about LAM Action!

As a charity set up to support people affected by LAM it's important for us to know how well we're fulfilling that purpose. We're aware that people come into contact with us in different ways and for a variety of purposes and we're keen to know what works well and how we can improve.

We have produced a short survey and with effect from **15th January** this can be accessed from our website and Facebook and Instagram accounts. Users of LAMLine and LAMTalk will also be sent a link to the survey. For anyone who receives a printed copy of LAMPost Jill will be sending you a paper copy of the survey.

We really would be delighted to hear the views of anyone who ever contacts us, not just members! Please do take a few minutes to complete it and help us to work on the things that matter to you – thank you!

The survey will go live on **15th of January** and can be accessed via the link below or by scanning the QR code.

<https://forms.office.com/e/gZ6diPcdzb>

**Sally Merritt-Collins and
Adam Davidson**





A Small Town, a Big Impact: The Wantage Christmas Card Sale

Every November, the quaint market town of Wantage, Oxfordshire, transforms into a hub of festive cheer and charitable giving. For over two decades, a dedicated group of volunteers has organized the town's Charity Christmas Card Sale, a heartwarming event that attracts both local residents and visitors.

The event is remarkably simple yet incredibly effective. A dedicated organizer books space at the local museum and invites charitable organizations to participate. There are no fees for the charities, making it a win-win situation. All the charities need to do is:

- **Deliver Cards:** Provide cards to the museum before the sale starts, along with a stock sheet.
- **Price Cards:** Individually price each pack of cards.
- **Volunteer:** Assign a volunteer to manage the stall for a designated time slot.
- **Collect and Record:** The volunteer on duty simply collects money and records the total.

This year, I participated in the sale on behalf of LAM Action for the first time. Despite initial concerns that I had about the charity's lesser-known status, the event proved to be a resounding success. By placing informative sheets that Jill kindly sent to me, alongside the cards, I was able to raise over £100.

I am also a committee member of our village hall, and inspired by the success of the museum sale, I decided to have a stall at our own small Christmas event in the village hall. I sold some more of the LAM Action cards remaining from the Museum sale, along with a few handmade items like sweet-filled snowman jars, filled Christmas favour boxes, and quiz sheets. This additional effort raised another £150, bringing the total to over £250 for LAM Action.

I have also placed a collecting box on the bar in our village pub, with information sheets alongside it.

While raising funds is crucial, increasing awareness of the condition itself is equally important. By participating in these local events, I was able to introduce many new people to LAM, and the LAM Action charity. Lots of people asked “What is this about?”. A doctor stopped to talk about it as he, himself, has never come across this disease before, and another scientist stopped to talk saying he had never heard of LAM at all until the previous week, when he had received an email out of the blue from an organisation online called Medscape, explaining about the condition. This increased visibility is vital, and can lead to future donations and support, ensuring the charity’s continued growth and impact.

As the saying goes, “From little acorns mighty oaks will grow.” The Wantage Christmas Card Sale, and the small village “Christmas Event” are a testament to the power of community and the impact that small, local initiatives can have on charitable causes.

Jess Matson





All aboard!

Down on the Farm

In 2023 our farm won the Bronze Chough Award for Excellence in Conservation within Commercial Agriculture. The Farm Wildlife Advisory Group arrange the judging and awards each year and asked if we could host a farm tour, which went ahead on 1st of September.

As an oxygen user I'm very conscious of accessibility so we arranged 5 tractors and trailers for the tour- no walking required! The turnout was much bigger than expected so we had a last-minute scramble for extra vehicles.

We were delighted to host 150 people, a mix of farmers and general public. It was really pleasing to see so many non-farming people taking an interest in what we do.

We spent a couple of hours looking at how our livestock, 650 ewes and 1000 April born lambs, are used to manage some special habitats.

We have an orchid meadow, rare anthills of the yellow meadow ant and rocky coastal areas, known locally as brooghs, where winter grazing is crucial to stop encroachment of scrub which would smother wildflowers.

The grazing of the brooghs creates ideal habitat for rare Choughs, of which there are only 400 pairs in the UK, and our shore fields are an important winter roost for Red Listed Curlew.

As our tour coincided with Love Lamb Week (1-7 September each year) Isle of Man Meats kindly supplied 12 shoulders of lamb, which were cooked in 5 kitchens by friends and family. We served 120 lamb baps- we'd thought we might get 60 people at the most!

Friends a family kindly baked a HUGE number of cakes and helped serve tea and coffee.

£955 pounds was raised, to be split equally between LAM Action and Isle of Man Agricultural Benevolent Trust.

The day was a great success, thanks to Rachel Moore who helps me on the farm, friends and family.

I post on Instagram most days if you'd like to see daily updates from the farm.

Anna Kerruish (@manxshepherdess)

Anna addressing the assembled crowds



Beautiful Manx Scenery



A fantastic turnout



A real cliff hanger!





Swim Serpentine

How long does it take to swim 2 miles round the Serpentine Lake in London's Hyde Park? In my case about 5 years...

Swim Serpentine is a two-mile swim which is one of the London Classic events – alongside the London Marathon and Ride London. In the autumn of 2019, I decided it would be a good challenge for me to raise money for LAM Action. I bought my place in the 2020 Swim Serpentine and joined an open water swimming class, which took place in an indoor pool. Along with my brother, Peter, and a group of about a dozen swimmers of varying abilities I began training to improve my swimming style, build stamina and practice some of the techniques required for open water swimming. I learnt about group starts, and the benefits of following in the wake of the person in front. I practised lifting my head out of the water regularly to make sure I was swimming in the right direction and I gradually increased the distance I could swim.

For the first term of lessons I used to finish the class feeling as though I had nearly drowned, because so much of the training involves swimming with only one arm, or with clenched fists or underwater. By the second term I was beginning to gain confidence and almost enjoying the process, but then, in the early Spring of 2020, Covid

arrived with social distancing, lockdowns and the closure of swimming pools. My class stopped and in the September Swim Serpentine was cancelled because of the increased risk associated with large gatherings. I carried my place over and decided to take part in the Virtual London Marathon for LAM Action instead.

Swimming pools were finally allowed to open again in the Spring of 2021, so I continued training. As the weather improved, I began visiting open water venues – lakes and reservoirs to gain more experience of distance swimming. When you swim 1000 metres to reach a marker buoy, which is just a tiny blue blur as you set out, you realise why lifting your eyes to check you are on course is important. I thought I was doing quite well but, when I checked the route on my watch afterwards, I could see that I swam in a series of zigzags.

I was all set to take part in Swim Serpentine in September 2022, but then we heard the news that it had been cancelled once again. It was the weekend of the Queen's funeral and it was decided that the event would involve too large a crowd when London was already busy with heads of state and visitors eager to pay tribute to the Queen. And so I continued going to swimming classes throughout 2023, with more open water training during the summer only to find that in September of that year the Serpentine had dangerously high levels of blue green algae and my entry was deferred once again. I had to wait another year to complete my challenge.

It was with great relief that I set off with my brother Peter on a bright September morning to travel to Hyde Park for the 2024 Swim Serpentine. I had kept up my training and was confident that I could swim the distance, the only concern was the water temperature. It was about 7 degrees colder than the temperature of the lake where I trained. So, armed with borrowed wet suit gloves, I joined the long queue to begin the event. Just under 5000 swimmers took part and we were all sent off in waves throughout the day. Each wave is ushered onto a floating pontoon and then at the appointed

time enters the water down a ramp to begin the swim. Peter and I held back so that we were not amongst the fastest swimmers and then dived in.

The water was certainly cold, but that provided a great incentive to swim faster. It took a while to get into my stroke, negotiating all the people who were swimming around me, but before long I got into a rhythm – head in the water, breathe out twice in time with two strokes and then head up to breathe and spot where the next marker buoy is before the next stroke. Along the route there are yellow buoys and large purple buoys to mark the turn at each end of the Serpentine and I made a mental note that I had to pass the purple buoys four times during 2 laps of the two-mile swim.



Canoeists are positioned along the route to help anyone who gets into difficulty and at one point I was approached by one. Over the sound of breathing and splashing of water I could just make out that he was telling me that I was swimming towards the wrong yellow buoy. I waved to thank him and altered course by about 60 degrees to avoid missing the next set of purple buoys.

There is a kind of mindfulness in long distance swimming. You lose yourself in the sound of the water and the bubbles as you breathe out. Occasionally I had to swim around slower swimmers or watch as other faster ones continued past me. I was aware that I needed to keep swimming hard to avoid getting too cold and by the time the purple buoys came into view for the fourth time I was beginning to imagine what it would feel like to finish. As

I clambered up the ramp at the end I heard for the first time the cheer of the crowds around the Serpentine and a swimmer beside me shook my hand and said “Well done”. We were both elated to have finished.

It took a bit of time to get warm again, but, after 5 years of training I had completed Swim Serpentine in 1 hour 23 minutes and 58 seconds. I was also chuffed to collect a London Classics medal at the finish, because I had taken part in all 3 London events – the Marathon and Ride London - all for LAM Action.



With thanks to my brother Peter for encouraging me to take part in the first place and joining me in training and my wife, Julie Mullins for providing support throughout the process and photos on the day itself and everyone who sponsored me.

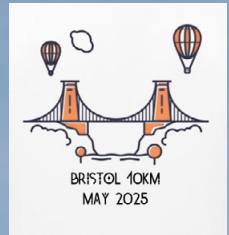
If you would like to contribute to my fundraising for LAM Action please go to:

<https://2024swimserpentine.enthuse.com/pf/david-mercer>

David Mercer

Editor's note: Well done David (and Peter!), a heroic effort once again and completing the 3 London Classics is an incredible achievement - take a well-earned bow!

Upcoming Event



The Great Bristol Run will take place on **11 May 2025**, and LAM Action Trustees Harriet and Adam Davidson have done an amazing job of recruiting over 50 of their family and friends to take to the streets of Bristol to raise funds for LAM Action. Please make a note of it in your diaries and come down and lend your support on the day. There are a few places left if anybody would like to join them, so please contact Jill Pateman if you would like to take part, and she can put you in touch.

The next edition of LAMPost will be out in the spring with a deadline for submissions of **April 12th** - thank you!

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For online donations, visit
www.justgiving.com/lamaction

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