

AUGUST 2024

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Fishermen's Friends

From the Editor's Desk



I think it's safe to say it has been a fairly drab summer for all of us, but never fear, because the Summer edition of LAMPost is here to spread some much needed sunshine!

Once again we have some interesting and inspiring articles that I hope you will enjoy reading, and I am hugely grateful to everybody who has contributed this time round. I think this may also be a first for LAMPost, as we have an article by a celebrated author, whose books have been read by many thousands of people around the globe. This just goes to prove that it really doesn't matter if you are a professional purveyor of prose, or somebody who might struggle when it comes to putting pen to paper – we welcome each and every article regardless of who has written it so please do consider if you might be able to contribute something for a future edition.

Big thanks once again to all our wonderful fundraisers who have been tirelessly raising funds for us to ensure that LAM Action can keep doing what we do – funding vital research, and supporting women with LAM in the UK. Every penny raised will do just that and we are extremely grateful for all your efforts. If your fundraiser is not celebrated on the following pages, then please let us know about it, as we love the chance to say thank you to you all properly.

We were delighted to finally get back to face-to-face meetings with our 2024 Annual Meeting back in June in Birmingham and you can read some more about it on the following pages. Please make a note in your diaries that the **2025 Annual Meeting will take place on Saturday June 7th**, and will once again be a face-to-face

format. We are yet to confirm the venue, but for now please keep the date free!

LAMPost will return just before Christmas, with a publication deadline of **December 12**, please email any articles or other contributions to:

lampost@office.lamaction.org.

Enjoy what's left of the summer and best wishes.

John

REMEMBERING CAROLE GRIST

Earlier this summer, we lost a long-standing member of our LAM community, Carole Grist. Carole was 76 and died peacefully on 4th July 2024 after taking ill on holiday in Hereford; apparently the previous day she “had been having a brilliant time with friends, whizzing around on her scooter”.

According to our former coordinator Jan Johnson, Carole was one of the first members of the LAM support community, always happy to offer her advice and experience to other women with LAM, particularly newly diagnosed patients. One of them, Chris Roylance, says that Carole was the first person she spoke to after officially being diagnosed with LAM. Jan had put them in touch with each other, and they met up regularly, together with another LAM lady, Yvonne Bates.

Carole lived in Lancashire with her late husband Brian, who died in 2020, and she attended LAM Action annual meetings until very recently. She is fondly remembered by her many friends as a lovely, small lady with lots of energy!

Gill Hollis



Carole at a LAM Action pre-meeting dinner in Anne Tattersfield's garden, 2007



(L to R) Yvonne Bates, Carole Grist and Chris Roylance in 2019



LAM Action's 2024 Patient Meeting

Finally, we managed to get people together! There was real excitement as over 50 people congregated at the Macdonald Burlington Hotel in Birmingham on Saturday 8 June.

It was the first LAM Action annual patient meeting for five years to meet in person. During the pandemic years, we've worked hard to deliver annual meetings online, thanks to the professional expertise of trustee David Mercer and his team. But 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. It was wonderful to see everyone again.

There was a good turn-out for dinner at the hotel the evening before, with faces old and new. The next morning, the meeting began at 9.30 and wrapped up at around 3.30, with a packed programme in-between, which is detailed on the following page. And we shouldn't forget the raffle, the Christmas card sales and the cake stall heaving with goodies!

Many thanks to everyone who contributed to the success of the meeting: the excellent speakers – including many from the LAM Centre in Nottingham - who gave up part of their weekend to be with us; those who baked cakes, donated raffle prizes and manned the stalls; and the organising committee, who ensured that the meeting content was interesting and that the event went smoothly. Finally, thanks to all who attended and participated with

such enthusiasm. Feedback suggested that some of the most popular sessions were those involving women with LAM discussing their own experiences, so special thanks to those ladies who opened up with their personal stories. We look forward to seeing you next year!

Gill Hollis

2024 Annual Meeting Programme

Coffee and Registration	
09:30	LAM Basics Prof Simon Johnson, Director of the National Centre for LAM, Nottingham
10:00	Welcome & AGM: Year in Review / Financials / Election of Trustees Leanne Lillywhite, LAM Action Chair
10:30	Research Update Dr Debbie Clements, Scientific researcher for LAM, Nottingham
11:00	LAM Patient Groups Around the World <i>(including live link with German LAM patient group's annual meeting in Mainz)</i> Leanne Lillywhite, Gill Hollis
Coffee Break	
11:20	Concurrent break-out sessions, with women with LAM discussing personal experiences: Pregnancy & LAM , facilitated by Dr Anneke Chu Menopause & LAM , facilitated by Dr Justin Chu
12:00	The Lucy Falconer Talk – The LifeArc (Virtual) Centre for Rare Respiratory Disease – how UK LAM patients will benefit from this £10m new project <ul style="list-style-type: none"> • Jo Pisani, trustee of LifeArc and LAM Action – overview of LifeArc and its commitment to rare disease • Prof. Simon Johnson – what the project will deliver for LAM research and how the LAM community can get involved • Philippa Thomas, LAM patient – how the patient voice is being included
Lunch	
13:30	Q&A with members of the National Centre for LAM team Prof. Simon Johnson, Dr Sy Giin Chong, Nurses Hollie Gorensweigh and Ali Hulbert
13:45	Exercise & LAM <ol style="list-style-type: none"> Benefits of home-based exercise in LAM – Dr Mary Beth Brown on the results of her University of Washington study with Claire Child (pre-recorded talk) Personal Approaches to Exercise and LAM – panel discussion with LAM ladies Alison Moxley, Roz Bushman and Clare Lyon, facilitated by LAM Action coordinator Jill Pateman Breathing & Exercise – Physiotherapist Rick Porter discusses breathing and leads us through simple breathing exercises Supplemental Oxygen and its Use in Exercise - Hollie Gorensweigh, LAM Centre specialist nurse
3.30	Final Remarks and CLOSE: Leanne Lillywhite
More tea and coffee!	





Keep on Running!

LAM Action has some runners taking part in two events in the coming weeks.

THE BIG HALF

Organised by London Marathon Events, The Big Half is a vibrant, inclusive half marathon with a fun, festival atmosphere. The 13.1 mile course weaves through London from Tower Bridge to the iconic Cutty Sark in Greenwich. LAM Action has 2 runners in the starting lineup.

Melody Klein Ovink is a Physiotherapist from London whose sister, Miriam has LAM. Melody was diagnosed with a rare condition which left her with an incomplete spinal cord injury. She has been doing rehabilitation for the last few years and running a half marathon was her final goal.

Melody said, "Earlier this year my sister was diagnosed with LAM. Because she lives in New Zealand, fundraising and bringing awareness to this condition through my half marathon was one way of being able to support her."

To add to Melody's fundraising total go to:

<https://2024thebighalf.enthuse.com/pf/melody-klein-ovink>

Daniel Mullins lives in Essex and is raising funds for LAM Action because of his aunt, Julie Mullins. Julie was diagnosed with LAM in 2007. Dan said, "Training is going well. Did a practice half marathon and ran 1 hour 49 minutes. Seeing the charity's incredible effect in its support and being inspired by other family members who have raised money for LAM Action, I could not think of a better charity to fundraise for."

If you'd like to support Dan's fundraising go to:

<https://2024thebighalf.enthuse.com/pf/daniel-mullins>

If you live near London and would like to support Melody and Dan the first wave of charity runners starts from Tower Bridge at 8.30 on Sunday 1st September. Then waves every 10 minutes until 10:00. For details of the route go to:

<https://www.thebighalf.co.uk/the-events/the-big-half>

THE GREAT NORTH RUN

The AJ Bell Great North Run is the world's biggest half marathon, with 60,000 runners taking on the 13.1-mile route from Newcastle to South Shields. It's famous for its inclusive atmosphere, unbeatable on-route entertainment, and warm Geordie welcome, not to mention the millions raised each year for worthy causes.

Katie Love is a Fire Officer from Stockton on Tees who found out she had LAM in 2007. She's taken part in the Great North Run 3 times before, but this is the first one for LAM Action. Katie wrote, "I'm lucky that I have been able to have a normal life but there are others that are not so lucky and benefit from support and research from LAM Action. Please if you can sponsor me - you will be helping all the Lammies of the UK." To do that go to:

<https://www.justgiving.com/page/k-love-1720122208103?>

And if you live in the North East and fancy supporting Katie you can find a map of the Great North Run route here:

<https://www.greatrun.org/events/great-north-run/>





The Lyme Museum: Shedding Light on Invisible Illnesses and Disabilities

The Lyme Museum is an innovative museum dedicated to exploring the lived experiences of invisible illnesses and disabilities. With a unique focus on materiality and storytelling, the museum aims to make the invisible visible, one flat lay and one story at a time.

The Lyme Museum offers a groundbreaking approach to understanding and raising awareness about invisible illnesses and disabilities. By collecting objects, stories, flat lays, and artworks, the museum provides a platform for individuals to share their lived experiences and challenge misconceptions surrounding these often-overlooked conditions. But it is so much more than just a collection of artefacts – it's a movement towards empathy, understanding, and inclusivity. With an education hub, digital platform, and international community, the museum serves as a beacon of hope and advocacy for individuals living with invisible illnesses and disabilities.

At The Lyme Museum, we believe that visibility is key to understanding and supporting those living with invisible illnesses and disabilities. Since its inception in 2020, The Lyme Museum has invited individuals from around the world to contribute flat lays of objects that

hold significance in their lived experiences. Participants were encouraged to share the items that surround them, regardless of their photography skills, resulting in a diverse and inclusive collection that challenges the notion of invisibility. From everyday items to personal mementos, these objects serve as tangible reminders that invisible illnesses and disabilities are not truly invisible – they are woven into the fabric of everyday life. The flat lays are a fantastic symbol, as they demonstrate that art and materiality exist everywhere. You don't have to be 'creative' or an artist, and you also do not need to hide what is fundamental in your life. The arrangement of the everyday objects and their connection to invisible struggles shed light and reinforce the importance of the seemingly mundane. They become little collages that foster conversations and inspire a desire to change the lack of focus placed on these conditions within society. By placing materiality, care, and emotion at the heart of our conversations, we hope to foster empathy, connection, and meaningful dialogue.

The goal is to challenge perceptions and amplify the voices of those often marginalised by society. Through the online exhibitions, we aim to create spaces for reflection, education, and advocacy. By sharing these stories and objects, we hope to inspire greater understanding, compassion, and support for individuals living with invisible illnesses and disabilities.

Join us on a mission to make an impact, where every object tells a story and every story has the power to change perceptions. Visit us online today and become part of our global community of storytellers and advocates!

Emilia Sharples, The Lyme Museum

www.thelymemuseum.org

[instagram.com/thelymemuseum](https://www.instagram.com/thelymemuseum)

[email: contact@thelymemuseum.org](mailto:contact@thelymemuseum.org)

The Lyme Museum is registered as a small museum in Leicester, UK with the Association of Independent Museums (AIM).





Eva Sarginson with her support team including parents Helen and Charlie Sabin

The Magnificent Seven!

LAM Action works hard to raise awareness of LAM through fundraising events so that the participants not only bring in money towards research but also learn something about the rare illness which affects their family member or friend. In this year's London Marathon there were 7 runners representing LAM Action in the London Marathon and all of them were linked in some way to the condition.

Eva Sarginson is Helen Sabin's daughter and a primary school teacher from Leamington Spa. Helen, who has LAM, her husband Charlie and their family organised a Valentine's Ball to help with Eva's fundraising and raised £2500 towards a total of £6830. Eva said, "My training and completion of this marathon was extremely tough, but it is just a small thanks in return for allowing me to have my Mum longer than I ever thought."

Jenny Hastings is a child protection officer from Cambridgeshire who was running to support a friend who has LAM. Jenny was injured last year so LAM Action carried her place over for her. It was worth it, because Jenny raised £1315. After the event Jenny said, "Thank you for allowing me to run for you and for letting me run the year after! I really enjoyed the whole experience

and you will be my first choice to raise funds for future events. “

Paula Snee, a logistics manager from Brighouse, was supporting her friend Saba, who has LAM. Paula won a place in the London Marathon ballot, so she didn't need to raise money, but she chose to do so for her friend. Afterwards she wrote about signing up on the Enthuse fundraising site, “So glad I did decide to raise funds for such a good cause, when I went on and it said I had to raise £500 I nearly didn't continue as I thought I would never hit that figure. So glad Amanda from work told me I would.” Despite her doubts Paula raised £1540.



Investment analyst **Harry Read** works in the City of London and is also a keen kick-boxer, golfer and traveller. He heard about running the Marathon for LAM Action from the Chair of the Executive Committee, Leanne Lillywhite-Sutton. That conversation brought in £2180 for the charity's research work.

Dr Justin Chu, an IVF consultant, was taking part because his wife Anneke has LAM. This was his second Marathon for LAM Action and this time he managed to raise £2778. Justin is very positive about the community aspect of LAM Action, “The charity has allowed Anneke and I to meet many women like her who have the disease. Talking to people with similar circumstances has been very helpful... We also believe that the funds that LAM Action receive may find a cure for the disease.”



Harry
Read



Justin Chu
and friend

Leagh Callow is the manager of the Netherclay Livery Centre, near Taunton and was taking part for her aunt Alex McDonald, who has LAM. Leagh's family raised money at a Christmas fund day at the livery stable which contributed £550 to a total of £3393. On Marathon day Leagh was supported by her aunt, along with other members of her family including her mum and husband, Dan. Leagh said, "This was my first time running in the London Marathon and I was really excited to take up the challenge to help raise funds and be part of the LAM Action team!"

Kevin Thomas, an accountant, was running in support of his cousin Eleanor, who has LAM and is due to take part in next year's London Marathon. Kevin's mum and dad turned out to cheer him along the route and at the finish. Kevin's total was £4486. In a note after the event Kevin wrote, "Thanks for the opportunity to raise money for a great cause, and to do the run... Talking to Eleanor more about things through this process has been great, definitely understand more of what she's been through. Fingers crossed the research gets some results!"

Please have a think about family and friends who might be interested in running the London Marathon in the future. Having a connection to a woman with LAM really does make a difference to the runner's fundraising and help to spread the word about LAM to the wider public.



Leagh Callow with Dan and her mum



Kevin Thomas with his parents

For more information about running the London Marathon or any other running event, please contact: **david.mercer@office.lamaction.org**

David Mercer

SAVE THE DATE!

JUNE 2025

S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
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29	30					

A purple arrow points to the number 7 in the calendar grid.

We hope all those who attended the LAM Action Annual Meeting on June 8th in Birmingham enjoyed it as much as we did!

It was fantastic to see so many old friends again and also to welcome some newer faces to our community. So much so, that we are already planning the 2025 meeting!

Please keep Saturday June 7th 2025 free for now – venue is still to be determined, but we really can't wait to do it all again...



Taking the High Road in Bonnie Scotland

The Big Fish fundraiser for LAM research involved a quite extraordinary challenge: to walk 100km, and to catch 100 fish in 100 lochs over 5 days and nights in the remote western Highlands of Scotland.

David Howie Scott and his son Louis hatched the plan and once committed to the idea, they called in their respective best friends Ali Fraser, Angus Forbes and James Wink. They picked a date in May and began training in earnest for the Big Fish.

The idea was to capture the imagination of friends and family so they would dig deep to support the intrepid 5 to raise as much as possible for LAM research.

Alison, David's wife and Louis' mum, was diagnosed with LAM 10 years ago so it was something which had been in their minds for a long time and this seemed the perfect thing to do.

David's restaurant Howies in Edinburgh has had a wine on the menu for years that every penny of profit from sales has been going towards LAM research - but this was on another scale altogether.

Training walks carrying 14kg packs, long discussions about equipment to take, and ways to beat the weather if required took up a lot of time. The idea was to catch 100 fish but to release all of them except the ones they would need to eat to sustain themselves on the monumental journey.

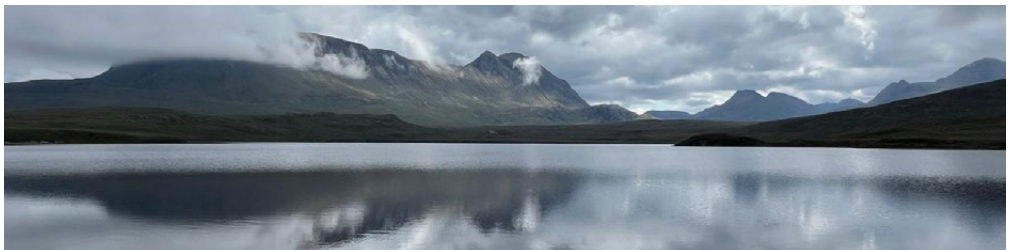
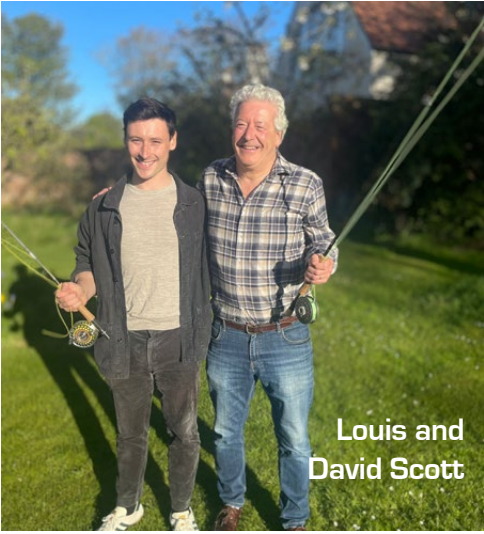
As the men set off optimistically, May 2024 conjured up the worst weather Scotland had seen in a long, long, time, as wild storms, winds and biblical rain poured down on them as they trudged through the remote Highlands. Refusing to be beaten, they continued with strength, determination and humour, though there were times when it seemed a near impossible task, pitching their tents at the side of a loch in a howling gale, teeth chattering they were so cold, but despite adversity they were all in it together and so hour by hour they stuck together like a tight band of brothers and yes the fish were caught, they found their lochs, and revelled in the extraordinary scenery, the laughs, the egging each other on, and most compelling of all - the reason they were doing it and the money that had been pledged kept them going.

And so, task completed they walked back to their starting point on day 6, weather beaten, exhausted, bedraggled, desperate for hot food, a roof over their heads and a meal that didn't have scales and a tail but thankful and elated they had completed an extraordinary journey for such a great cause and they were astounded to have raised **over £21,000** - every penny of which will go directly to LAM Action to support Professor Simon Johnson and his endeavours to find a treatment and cure for the condition.

Thanks to everyone who supported them in their endeavour and for the generosity shown by all. They were best friends before the adventure, and now they feel like brothers.

Some of these pictures give a flavour of their experience, highs, lows and moments of sheer joy.

Alison Craig



LAM Action supporters Derek Adam, Paul Murray, Andy Charalambous and Darren Whitney on the 9th green



Getting into the Swing for LAM Action

We were up with the dawn on Saturday July 13th to support the Captain's Charity Day at Aldenham Golf and Country Club, part of my best friend and Club Captain Simon Veysey's year of fundraising for LAM Action.

Arriving at 06.00 for setup, there were already a few players ready to head out on the course, and I was soon put to work sitting next to Treasurer Ian Mackie, who was collecting all the entry fees from the players, while I was handing out raffle tickets and score cards to those who were participating in the event. By 11.30 some 130 members and guests had entered and were out on the fairways, so time for a quick breather before heading out to the 'halfway house' refreshment station which was being manned by Simon's partner Laura and his daughter Abbey.

Aldenham Golf Club had kindly provided a complimentary barbecue for the hungry golfers and there was no shortage of takers for the burgers and hot dogs on offer. Out on the course, there were some good scores being made, others not so good, but everyone was thankful it was a warm and dry day, unlike the previous Saturday which had been a complete washout!

By around 4.30 everyone was home and hosed and enjoying some well-earned refreshment, with some heading home, and others staying for the evening dinner

which was going to kick-off at 7.00pm. Nobody really knew what to expect from the 'Dingo Bingo' which was to be the entertainment, but we were soon to find out. The catering staff had excelled themselves in providing a delicious Italian style buffet and the 70 odd people who attended the dinner were left loosening their belts and hoping that there wouldn't be too much audience participation to come (fat chance, if you excuse the pun!).

Simon gave a lovely speech to thank everyone who had helped make the day so successful and then there was barely a dry eye in the house when my wife Sarah took to the mic for a speech that explained what LAM is and the incredible work that LAM Action does on behalf of patients, and also her personal journey with the condition. The raffle was drawn and then a short auction of the more valuable prizes on offer also raised a great amount for the charity.

After that it was eyes down for a gloriously bonkers session of 'Dingo Bingo' which combined traditional bingo with a lot of music and dancing and the downing of shots, all expertly compered by Dave and Andrea Rawson who had travelled all the way from Leeds to host. Huge fun was had by all and finally one lucky winner got a full house and took home Dingo the Dog. After some fierce competition between the tables, the LAM Action table emerged victorious to claim the crown of boogiemasters, no mean feat considering Sarah had left her oxygen at home! If you are ever holding your own event and looking to book some entertainment, then google Dave Rawson Comedy Hypnotist and you will be guaranteed a fun packed evening.

All that remains is for me to thank Simon, Laura, Abbey, Ian, Hoss, Bradley, and everyone else at Aldenham Golf and Country Club for a spectacular day that will live long in the memory. Simon's fundraising for us will continue until he stands down as Captain in October, when we will learn the final tally that he has raised on our behalf.

Thanks also to all the members and guests who came to play golf, and the companies or individuals that sponsored a hole or provided raffle and auction prizes. A special shout out to RnD Systems Integration for sponsoring the gifts as well as holes, Muse Medical Aesthetics, Amber Associates IT Training, NA Edmunds Decorating, Olly from Group One Land Rover, Topgolf Watford and Harvey Waywell.

John Wood



Simon and the LAMPost Editor on the 1st tee



Thanks mate!



Hoss, Simon & Laura at the halfway house



Hoss with his prize of Dingo the Dog

The next edition of LAMPost will be out just before Christmas with a deadline for submissions of **December 12th** - thank you!

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For postal donations, please make cheques payable to "LAM Action" and send to:

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

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