APRIL 2025

LAMPost

LAM ACTION
Supporting women with
Lymphangioleiomyomatosis

Promoting Rare Disease Day

From the Editor's Desk

As we go to press there are about 6 weeks left until the Annual Meeting on Saturday June 7th, and we are very much looking forward to seeing some old faces as well as welcoming some new ones. You can find more info on page 5 and if you haven't yet booked your place and would like to join us, then please contact Jill Pateman.

If you are intending to come to the meeting, we would be most grateful if you could submit questions in advance about any symptoms that leave you wondering if they might be linked to LAM. The issues raised will be discussed by a panel made up of LAM Centre clinicians in the final session of the afternoon. If you have any symptoms that you're not sure about, and would like advice on what you should do, please email Jill Pateman **by the end of May,** including ANNUAL MEETING - SYMPTOMS as your email title, so that we can ensure your questions are passed on to the team.

This is always an exciting time of year as our biggest fundraiser, the **London Marathon** is just around the corner on **Sunday April 27th**. Once again we will be well represented by 6 runners who will be taking part to raise funds for LAM Action, and you can read all about them on page 11. Big thanks and good luck to you all. It really is a fantastic day out, so if you are able to come down and lend your support then all our runners will greatly appreciate it.

Not forgetting the other big event on the horizon, the **Bristol 10K** which is taking place on **Sunday May 11th**. The streets of Bristol will be ablaze with green and purple LAM Action logos as we have an incredible 50+ runners taking part on our behalf and big thanks to Harriet and Adam Davidson for managing to recruit so many participants. There are still a few places up for grabs though, so if you would like to join them, please contact Jill who will put you in touch.

The LAM Action Committee are delighted to welcome **Clare Lyon** as a new Trustee. Clare will be well known to many of you already and we are excited to have someone with so much experience in the field of Biological Science on board. For those who don't know her, our PR company Empica recently ran an article on Clare and we have reproduced this in full on page 15.

A big thanks to everyone who contributed to this edition of LAMPost. We will return at the end of the summer, with a publication deadline of **August 12**, please email any articles or other contributions to: **lampost@office.lamaction.org**.

Until then enjoy what sunny weather will hopefully be coming our way over the next few months, best wishes,

John

A massive **THANK YOU** to everyone who took the time to complete the recent online survey into how LAM Action are performing.

The committee are currently working through the results, and we will hope to share these with you in the next edition, so please stay tuned.

Cover photo:

Hollie Gorensweigh and **Suzanne Swann** helping raise awareness of LAM and other rare cystic lung diseases on Rare Disease Day, February 28th at QMC Nottingham. There was lots of interest from passing visitors and Suzanne had a section of LAM lung to look at under the microscope which was very popular. Thank you both for helping to put LAM in the spotlight!

Saturday June 7th

Leonardo Hotel London Watford
31-35 Clarendon Road,
Watford, Hertfordshire,
WD17 1JA

LAM Action Annual Meeting 2025

This year's annual meeting will have something of interest to everyone with LAM, as well as their family and friends. In addition to the formal Annual General Meeting of the charity, the day will include:

- A discussion about common symptoms associated with LAM and how best to deal with them
- A session about how to regain fitness or use pulmonary rehab after illness
- Family and friends will be able to attend a break-out session specifically for them
- Those with LAM will be able to benefit from a break-out session focused on breathing techniques

Of course, no meeting would be complete without a discussion of research surrounding LAM, and so we will include presentations about the prevalence of LAM, ongoing research, drug repurposing and the importance of patient engagement in rare respiratory disease.

There will be plenty of time to meet new people and catch up with old friends – with coffee/tea breaks, lunch and perhaps a cake stall and raffle throughout the day.

Please note that the meeting this year will not be streamed live and will be in a purely face-to-face format. We feel that the benefits of meeting in person once again cannot be overstated.

The Agenda for the Annual Meeting* is as follows:

Timing	Topic
09:30-10:00	**LAM Basics**, presented by Professor Simon Johnson, Director National Centre for LAM; Professor of Respiratory Medicine; Head of Division of Respiratory Medicine, University of Nottingham; Co-director Rare Cystic Lung Disease Collaborative Network
10:00-10:30	**Formal AGM**
10:30-11:00	**LAM Prevalence and Other Research**, presented by Cormac McCarthy, Associate Professor and Deputy Director Clinical Research Centre, University College Dublin
11:00-11:10	Coffee break
11:10-12:00	**Lucy Falconer Keynote Address – Patient Engagement in Rare Respiratory Disease**, presented by Dr Sam Barrell, Chief Executive Officer of LifeArc
12:00-13:00	Lunch
13:05-13:30	**mTOR Pathways Diseases Node and LAM**, presented by Professor Joseph Bateman, lead investigator, from the Department of Basic and Clinical Neuroscience, King's College London
13:30-14:00	**Recovering Pulmonary and Physical Fitness After Illness**, presented by LAM Centre clinicians and Rick Portard, BSc in Physiotherapy and MSc in Advanced Rehabilitation
14:00-14:10	Coffee break
14:10-14:40	Break-out sessions: • **Family and friends discussion** • **Breathing techniques**
14:40-15:10	**Research Developments,** presented by Dr Debbie Clements
15:10-16:00	**Is "This" Related to LAM?** A discussion of the varied symptoms and problems many of us experience and what we should do about them, led by LAM Centre clinicians with questions and input from LAM patients **General Q&A** **Close of Meeting**

** Subject to slight variations in timings*

London & South East Support Group

The London and South East regional support group recently met up in Central London for their regular 6-monthly catch up. They were asked to write down their thoughts on how meeting with other ladies with LAM benefited them.

“It’s good to talk to others who understand your experience first-hand.”

“The social aspect and meeting other people with the same illness.”

“LAM is such a rare disease so it’s nice to know I’m not alone. Also, nice to see old, familiar faces and catch up, whilst also meeting newly diagnosed patients. It’s not all gloom; we get together and have a laugh too!”

“I like coming to LAM coffee events because it gives me an insight of what other LAM ladies are or have experienced.”

“So good to meet face to face with the London Lammies and compare notes on how we are doing. Other topics also come up!”

“Lovely meeting and very beneficial catch-up. Well done Sarah and all for sharing.”

“It’s always good to talk about symptoms and how others cope.”

The next group meeting will take place in **October**, if you are newly diagnosed and would like to join the group, please contact Jill Pateman.

Could YOU coordinate your own regional support group?

Before the pandemic, we had other regional groups who would meet up in the North West, North East, West Midlands, M40 corridor and South West.

These were replaced with online meetings which were segmented along age groups rather than regional areas (see page 18 for latest timings). With face to face meetings now becoming the norm again, we think it could be time to revive or kick-start some of the regional groups.

If you would be interested in coordinating a group in your area then please contact Jill to discuss the possibility.

The staff at Howden Eastleigh taking part in the Dress Down Day

A Right Dressing Down

A big thank you to Ollie Marshall and everyone at Howden Insurance in Eastleigh who took part in the company dress down day on Rare Disease Day, February 28th!

Ollie Marshall, 25, an Insurance Consultant at Howden Eastleigh, was joined by the local office team in a dress down day to raise money for LAM Action, and to support his mum, **Sally Carver**, who has been living with the condition for many years now.

Ollie explained: “My mum was diagnosed when I was two years old, so I’ve only ever grown up knowing my mum with this condition. She was only 38, a non-smoker and lived an active life so it was a shock to her when she got her diagnosis. She had to leave her job as a nurse and there were times when she would have to rush to hospital unexpectedly. It was difficult to navigate, especially as initially she was given about 10 years to live.”

Sally said: “It started as chest pains and shortness of breath, so LAM patients are often misdiagnosed with asthma, but then I collapsed whilst pregnant in 2001 and was diagnosed three months after Ollie’s younger brother was born. There was no treatment until I was offered to start a trial drug in 2005 in Nottingham, where the UK

LAM Action Centre for all patients is at Queens Medical Centre. The drug slowed down the disease and I've been on it ever since. Early diagnosis is vital, and research meant I benefited from the drug before the need for a lung transplant to be the first option for quality of life."

Ollie continued: "Since then, mum has been on this drug (Rapamycin) for the longest time of any LAM patient in the world. I really feel so lucky that my mum was always there for me throughout my life, despite everything she's gone through. That's what has motivated me to fundraise for LAM Action, and hopefully raise awareness of the disease, as it is so rare."

John Chapman, Client Service Manager at Howden Eastleigh, said: "At Howden, we're big believers in being a force for good, and Ollie absolutely epitomises that. When he shared with the team the journey his mum and he have been on, and how he wanted to give back, we were beyond proud to help."

On 28th February, the team at Howden Eastleigh joined Ollie in wearing green and purple, raising a fantastic **£417** for the charity. Howden are also hoping to support us with other future fundraising, which is amazing news.

A great big thank you once again from all of us at LAM Action!

Ollie with his mum and dad

London Marathon 2025 Preview

Started in 1981, the London Marathon has become one of the world's top marathons and its biggest one-day fundraising event. On Sunday 27th April thousands of athletes will set off from Greenwich on the 26.2 mile route that finishes on the Mall, this year LAM Action has 7 runners taking on the challenge to raise funds for the charity – most of them are connected to LAM in some way.

Eleanor Ward works in Adult Social Services and lives in Northamptonshire with her two cats, she's currently studying for a master's in social work. Eleanor has LAM and is running to keep her lungs fit and healthy for as long as possible, she's also keen to raise awareness of the condition.

Eleanor said, "My journey with LAM began at just 19 when I was diagnosed after enduring a series of pneumothoraxes. The following years were marked by chest drains, lung surgeries, and the removal of a large kidney tumour, ultimately resulting in the loss of one of my kidneys. Today, I live with ongoing breathlessness and another kidney tumour. This means that I will be running the marathon with less than 80% lung capacity. I'm deeply honoured to be the first person diagnosed with LAM to run the London Marathon for LAM Action."

To help Eleanor reach her fundraising target go to:
www.justgiving.com/page/eleanor-ward-1720954031153

Andy Judge is a barrister, living and practising in London. He has run the London Marathon twice before on behalf of LAM Action and hopes to improve on his previous times.

Andy said, "It is such a brilliant day and there is always a fantastic turn out from the public. I was introduced to LAM Action through my girlfriend, Katie, who has worked with David Mercer in the past and helped with LAM Action's Virtual Meetings. Since then, I have read about the charity and the incredible work it does for women with LAM. I hope that the money I can raise will go some way to helping those who need it."

Please visit Andy's fundraising page:
https://2025tcslondonmarathon.enthuse.com/pf/andrew-judge

Mark MacNaughton is a business development manager who lives near Cambridge. His wife, Jurgita, has LAM. Between 2017 and 2020 Mark ran 10 half marathons and is now taking on the marathon. Mark had to pause his training for a while because of a meniscus tear to his knee, but he's now back to fitness.

Mark said, "I am running the London Marathon for the first time and my inspiration to participate in this iconic event is my wife, Jurgita who was diagnosed with Lymphangioleiomyomatosis (LAM), following invasive surgery to fix a collapsed lung."

Eleanor Ward

Andy Judge

Mark MacNaughton

To support Mark please visit:
https://2025tcslondonmarathon.enthuse.com/pf/mark-macnaughton

Simon Fairbrother is an engineer from Bewdley in Worcestershire. He's a friend of LAM Action Trustee, Sally Merritt-Collins. In the past Simon has taken part in Ride London and the Royal Parks Half Marathon for LAM Action – this is his first marathon.

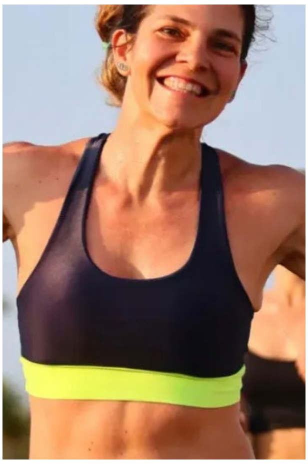
Simon commented, "In my youth I was a keen runner, being a member of Stourport Athletics Club, participating mainly in Cross Country races. Unfortunately due to breaking my pelvis in a car accident I was forced to stop running, turning to cycling, a passion I carry on today. Always keen to take on new personal challenges I returned to my childhood passion for running in 2018, through Parkrun, which ultimately led to taking on the Royal Parks Half Marathon in 2023. I'm very proud to be taking on the London Marathon in support of LAM Action and the fact that Sally lives with LAM makes it even more important to me."

Simon's fundraising page is here:
https://2025tcslondonmarathon.enthuse.com/pf/simon-fairbrother

Ellenor Rixon is an account manager for a soft drinks manufacturer and lives in London. She is a family friend of Julie Mullins, who has LAM. Ellenor has twice taken part in the London Landmarks Half Marathon and completed the Edinburgh Marathon in the last year.

Simon Fairbrother

Ellenor Rixon



Jamile Muller

Ellenor said, “The London Marathon has always been on my bucket list and it’s a privilege to be able to represent LAM Action whilst doing so after one of our close friends was diagnosed over 10 years ago. My goal is to run sub 3 hours 30 minutes whilst fundraising as much as possible to help aid better research and development into treatments and interventions for LAM.”

To help Ellenor achieve her target go to:
https://2025tcslondonmarathon.enthuse.com/pf/ellenor-rixon

Jamile Muller is a legal psychologist who lives in Sao Paulo, Brazil. She is travelling to London to take part in the London Marathon with a group of friends who all wanted to raise money for small medical charities.

Jamile said, “For me, running is more than a sport: it is an act of overcoming and transformation. Training at dawn, in harmony with nature, is when I find connection, strength and inspiration to face the day’s challenges. It’s MY moment.

I started running in 2020, during the pandemic, and over time, it became a habit that my body adopted. I run because it fits my routine, organises the mind and challenges the physical. Am I in-love-with-running? We have not reached this level of commitment yet… but I am not giving up!”

Jamile’s fundraising page can be found here:
https://2025tcslondonmarathon.enthuse.com/pf/jamile-muller

If you happen to live near London and fancy coming along to the route to cheer on the runners please contact david.mercer@office.lamaction.org **so that he can let our runners know to look out for you. There will be a LAM Action team waiting under the L sign on Horseguards Parade to welcome runners and their families after they have finished.**

David Mercer

Clare Lyon's Journey with LAM

Clare Lyon, who lives in Cambridge, first experienced health issues during her pregnancy in 2009. However, it was not until 2015 that she received a definitive diagnosis of Lymphangioleiomyomatosis (LAM), a rare lung disease. Her journey from experiencing unexplained health problems to becoming an advocate for rare disease research provides valuable insight into the challenges and resilience of LAM patients.

Delayed diagnosis and early symptoms

Clare's initial symptoms appeared during her pregnancy when she suffered from recurrent pneumothoraces (collapsed lungs). Following these episodes, she underwent pleurodesis surgery on both lungs at different times. A biopsy taken during one of these procedures did not reveal LAM, and doctors initially attributed her lung collapses to her tall, slim physique, which is sometimes associated with spontaneous pneumothorax.

Despite this explanation, Clare continued to feel that something was not right. She pursued further medical investigations, and a CT scan eventually revealed cysts on her lungs. This led to her referral to a specialist team in Nottingham, where she was officially diagnosed with LAM in 2015.

Emotional Impact and Treatment

Receiving the diagnosis was a mix of relief and anxiety for Clare. While it was helpful to finally put a name to her condition, she was deeply concerned about her future, particularly as a mother to a young daughter. Her primary worry was whether she would be around long enough to see her child grow up.

Since her diagnosis, Clare's lung function has gradually declined. However, in late 2023, she started treatment with sirolimus (also known as rapamycin), a medication that has helped stabilise her condition. She reports that her lung function is now stable and generally good.

Adopting a Proactive Approach to Health

Recognising the importance of maintaining good health, Clare took a proactive approach to her well-being. In 2016, she resolved to get herself into the best possible physical condition to prepare for any future deterioration. However, she had long struggled to find an exercise routine she enjoyed. Her negative experiences with PE in school had left her with little enthusiasm for physical activity.

That changed when she discovered Jazzercise, a dance-based aerobic workout with strength training elements. She fell in love with it immediately and became dedicated to her fitness routine. By 2019, Clare had become so passionate about Jazzercise that she trained as an instructor. She has now been teaching classes for over five years and credits her fitness level with helping to maintain her overall health. Despite experiencing another pneumothorax in 2022, her recovery was strong, and she has managed to avoid chest infections, a common complication for many LAM patients.

Living with LAM and Managing Symptoms

Although Clare's condition has stabilised, pneumothorax remains an ongoing issue. She describes the unusual sensation that precedes a lung collapse as a "cracking and popping" feeling, comparing it to the sound of water glugging from a cooler bottle. While alarming, she has learned to recognise the symptoms early and seek medical attention when necessary.

Pleurodesis surgery, which she underwent three times, has been instrumental in reducing the severity of her lung collapses. The procedure involves adhering the lung to the chest wall to prevent further collapses. Although not a complete cure, these procedures have helped her manage her condition more effectively.

Professional and Advocacy Work

In addition to teaching Jazzercise, Clare works for the University of Cambridge as part of the Teichmann Group, which is involved in the Human Cell Atlas project. This international initiative aims to map and analyse human cells at an unprecedented level. Within her role, Clare focuses on research ethics, governance, and patient and public involvement.

Her professional experience, combined with her journey as a patient, has led her to take an active role in advocacy for rare diseases. She has recently become a trustee for LAM Action and is involved in the LifeArc Rare Disease Translational Challenge. Additionally, she contributes to the mTOR pathway diseases section of Rare Disease Research UK, helping to bridge the gap between scientific research and patient needs.

Rare Respiratory Diseases Event

On March 4, Clare attended a landmark event bringing together patient groups, clinicians, and researchers focusing on rare respiratory diseases. The gathering represented a significant step forward in fostering collaboration across disciplines. Clare believes the event will enhance understanding between researchers and patients, ensuring that scientific advancements translate into tangible benefits for those living with rare conditions.

Judith Skorupski, Empica

Online Meetings

We have two upcoming zoom meetings for our age related support groups. If you have not taken part before and would like to join your relevant group, then please contact **Jill Pateman by Wednesday April 23rd** and she will be able to provide you with the link for joining the meeting.

JADE GROUP

For women born between 1960 and 1980

LAVENDER GROUP

For women born 1960 or earlier

The ***Jade Group*** meeting will take place on **Monday 28th April 18:30 - 20:00**

The ***Lavender Group*** meeting will take place on **Wednesday 30th April 18:30 - 20:00**

We are currently looking for a co-ordinator for the ***Green Group*** (born after 1980) - if you are interested please get in touch with Jill.

Pulmonary Rehabilitation - Just Do It!

I am currently mid-way through my third programme of pulmonary rehabilitation (PR) having completed one course just after my diagnosis with LAM in 2010 and my second course last year.

PR is an education programme that is designed to help us manage our lung conditions. Exercise is known to keep us as fit as possible and during the programme you are progressed according to your ability. You are taught to monitor your symptoms and how to deal with breathlessness exacerbations. You learn how to manage your own symptoms in order to get on with enjoying life.

PR is a multidisciplinary led programme that was originally designed for patients with COPD. The lead clinician is usually a physiotherapist and the programme runs twice a week for six weeks where participants spend one hour exercising and another hour taking part in an information session type lecture. The hope is that when taught your exercises and limitations you will continue with them after the programme has finished.

It has been acknowledged that patients with other lung conditions such as asthma, bronchiectasis and

ILD could also benefit from this programme and so in recent years it has been opened up to them too. Access to these courses varies across the country and the main constraints are funding by primary care, the location of the courses (hospital or community based) and timings of the courses, especially if people are working or have other commitments. Organisers are now exploring more innovative ways of offering these courses such as personally designed home based courses as well as video telerehabilitation courses to increase access and uptake.

The benefits of exercise are many but are often counter-intuitive if you have a lung condition such as LAM. Getting breathless can often be frightening but PR points out that doing exercise and getting short of breath can sometimes actually be good in that it is a normal response to exercise, that we shouldn't avoid activities that make us short of breath and that becoming more physically active can help us to control our breathlessness better. Doing PR, supervised by a physiotherapist, shows ways to monitor and measure this in a safe environment.

The types of exercises are cardiovascular training (endurance) such as walking on a treadmill or shuttle walking, using an exercise bike, squats, doing step ups on a small bench and sit to stand from a chair. There are also strength training exercises using bands and/or weights where legs and arms are the focus of the activities. All of these activities are tailored especially to each participant with both the length of time for cardiovascular training and weights or band colours are specifically prescribed for each person. Before any exercise begins there is a short warm up session and afterwards a cool down period.

After participating in each exercise you then have to assess the effect of it on your body in one of two ways. For cardiovascular exercises the BORG scale is used to see how breathless they make you. The BORG scale measures how breathless you are and ranges from “not short of breath” = 0 to “extremely short of breath” = 10. It is recommended that you should feel moderately short of breath = 4 after these types of exercise. After the strength training exercises a “rate of perceived exertion level” scale is used. Very light = 6 and very, very hard = 20. Each participant records the effects in their log book and if it appears that you can push yourself further in the following session timings, weights or reps are increased. Conversely, if you struggle with a certain exercise they can be reduced. Your performance is monitored and observed closely by the physiotherapist and if you or they have any concerns you can rest accordingly.

The second part of the PR session provides education talks that range from anatomy and physiology of the respiratory system, managing breathlessness, diet and nutrition, how to use your inhaler correctly, the benefits of exercise to maintaining your progress after the course. These sessions are given by experts in their fields such as nurses, occupational therapists and dieticians and are extremely useful in providing background and evidence for continuing to live well and healthily after the programme ends.

If you are referred for PR by either your GP or hospital consultant and are accepted onto the programme you are assessed not only on your strength and endurance capacity but also your quality of life and anxiety levels. These are then measured at the end of the course and improvements noted.

I am lucky to live in an area where a course of PR is funded for respiratory patients every year. We can self-refer but because I use ambulatory oxygen I get picked up automatically by the respiratory service after my annual oxygen assessment. I acknowledge that every region will have very different practices but would recommend LAM patients to explore their local provision if it would be of use to you! PR is a recommended treatment by NICE and so we are entitled to be referred.

I hope that my progress this year will be as good as last year's because I certainly improved in all areas of exercise tolerance and general well being. I have also enjoyed meeting other local residents with various lung conditions, not just with COPD but also asthma, other ILDs and one lady who suffered severe burns to her airways. I am also a patient ambassador for the programme and get asked to support and encourage others who are either thinking about joining the programme or who need information on how it works from a patient perspective.

If you get the opportunity to go on one of these programmes I cannot recommend it highly enough!

Sarah Wood

The next edition of LAMPost will be out at the end of the summer with a deadline for submissions of **August 12th** - thank you!

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