

APRIL 2024

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Spring is Finally Here!

From the Editor's Desk



With the Boat Race and Grand National now done and dusted it can only mean one thing - Spring is well and truly here and it's time for another edition of LAMPPost! We even got a quick blast of sunshine this past weekend, a welcome respite from the almost incessant wind and rain lately, and hopefully a portent of better days to come for us all.

As I write, the Committee are putting the final touches to the plans for the 2024 Annual Meeting and you can read the details on page 4, please note the deadline for booking rooms under the special rate is **April 26th**. It would be fantastic to see a mix of both old faces and new, and it promises to be a lovely day and the chance to rekindle acquaintances and make new friends that has been denied to us over the last few years.

A big thank you and good luck to the Magnificent Seven who will be running the London Marathon on **Sunday April 21st** to raise funds for LAM Action, we know you will all do us proud, so please come home safely and enjoy the day. If you live in the South East and you are at a loose end that day, why not come into London and cheer our runners on as they go past? It really is the most uplifting occasion and our runners will be grateful of any support you can muster. You can also help them reach their fundraising targets by visiting their links in the London Marathon feature on page 11.

We finish this edition of LAMPPost with a good news story, and there was also some more good news recently with the LAM Talk post announcing that **Michaela Bradley** had been discharged from hospital and is now back at home

following her double lung transplant back on December 29th 2023. Everyone at LAM Action sends their best wishes to you Michaela, and we hope you will continue your recovery on what has been a very long journey for you.

A very big thank you to everybody that has contributed to this edition of the newsletter, and made it possible and we look forward to receiving some more contributions to the next edition - if you haven't written anything for us before then please don't be shy!

LAMPost will return at the end of the summer, with a publication deadline of **August 20th**, please email any articles or other contributions to:

lampost@office.lamaction.org.

Until we meet again in Birmingham!

John

Get ready to have your say!

Following the LAM Action Strategy day last November the Trustees are keen to make sure that we are providing the best possible service to anyone who contacts us. They are currently working on producing a survey and this will be made available shortly. They look forward to hearing your views on how we can improve!



Well done and thank you to **Nick Woodhouse** for running the Middlesbrough Half Marathon on the 3rd of March 2024, romping home in an amazing time of 1 hour, 50 minutes and 19 seconds - raising well over £1400 for LAM Action in the process!



Cover Photo: Anna Kerruish, AKA The Manx Shepherdess, and one of her lovely spring lambs



LAM Action 2024 Annual Meeting

The LAM Action 2024 Annual Meeting will take place at the Macdonald Burlington Hotel, Birmingham, on **Saturday 8th June**, and we hope you will be able to join us. Please note 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 and we are looking forward to seeing old friends again as well as welcoming the many new faces who have joined the UK LAM community in the few years since we last held a face-to-face meeting.

The day delegate rate the hotel is charging us is £49 per head and LAM Action will cover this cost for all LAM patients and up to one person accompanying them.

As we are aware that some of you will be travelling quite long distances, we have arranged for a number of hotel rooms to be reserved for those attending the meeting.

Rooms for single occupancy on a bed and breakfast basis are available at a **cost of £127**. This is a special

rate available as part of the deal negotiated with the hotel. To reserve a room please contact the Reservation Centre on 0344 879 9000 and use **Booking Reference LAMA070624**. LAM Action will further subsidise every room booked by £49, please ensure you keep your hotel receipt so that you can claim this extra discount afterwards.

Rooms **must be reserved by 26th April**, at which time they will be released for general sale. Rooms may be available after that date, but they will be subject to availability and at best available rates. Full prepayment is required at the time of booking and once confirmed bookings are non-refundable and non-transferable.

Check-in is after 3pm on day of arrival, and checkout is before 11am on day of departure.

For those staying overnight we will book a table for a meal the night before. This will be from the hotel's general menu. If you would like to join us, please let Jill Pateman know so that she can ensure there is enough space to accommodate everybody.

We really would like to encourage as many people as possible to attend, so if anyone is struggling to pay for their travel, please apply to Jill in confidence as some assistance towards your costs may be available.

PROVISIONAL AGENDA

- | | |
|-------------|---|
| 09:00-10:00 | Coffee & Registration |
| 09:30-10:00 | LAM Basics |
| 10:00-10:30 | AGM: Year in Review/Financials/
Election of Trustees |
| 10:30-11:00 | Research Updates with Debbie
Clements |
| 11:00-11:10 | Worldwide LAM Groups |
| 11:10-11:25 | Coffee & Comfort Break |

11:25-12:00 Break-out Sessions:
(to run concurrently)

- Starting a family and pregnancy
- Menopause and practicalities
- Role of a LAM Action Trustee [TBC]

12:00-13:00 Lunch

13:00-13:15 Q&A with Prof Simon Johnson

Fitness and LAM

13:15-13:35 LAM and exercise

13:35-14:05 Panel Discussion: LAM patients discuss their personal approaches

14:05-14:25 Breathing and exercise

14:25-14:55 Incorporation of supplemental oxygen into fitness routine

14:55-15:10 Coffee & Comfort Break

15:10-15:55 Keynote Speech: LAM and Rare Disease Research

15:55-16:00 Close



The hotel is 1 minute walk from Birmingham New Street station. For parking and other info please visit this link:

<https://www.macdonaldhotels.co.uk/burlington/guest-information/how-to-get-here>

We would be most grateful for any raffle prize donations, please let Jill Pateman know if you can contribute some prizes. Or if you would like to bake some cakes for us to sell at the cake stall that would be wonderful, please bring them with you on the day. Thank you!



LAM patient Georgia with her boyfriend Jake and parents Miles and Donna

Love was in the air at the Valentine's Ball

Last year when my daughter Eva said she would like to run the London Marathon to raise funds for LAM Action I wasn't all that surprised! Eva has been running for 10 years. Her love of running started at the age of 16... but with all the training such a challenge necessitates her love for the sport dwindled somewhat! The dwindling love, however, has been a little re-energised by the amount of money we raised at the Valentine's Ball organized to help her raise money to warrant her place in the marathon. Her current tally stands at over £3500 and she is now aiming to raise in excess of £4k.

Once her place to run the London Marathon was confirmed we made a plan to organize a number of events to raise money. However, sadly my father-in-law became quite ill and died in September 2023 so the months leading up to this were quite busy and our plans were left behind. The stress of trying to raise money, train, and work (Eva is a teacher) was a little too much for her so we discussed the idea of doing one big event. I took over the mantle and in a short period of time, and with the help of some fabulous friends we organized a Ball in aid of LAM Action. This was the Valentine's Ball.

My friend Pinky helped me search high and low for a suitable venue. Many of the venues we visited were either too big or too small. Too big would have been a worry as it was all happening very quickly and I wasn't convinced I'd be able to fill the venue, too small and it just wouldn't be financially viable. We finally found The Orangery at Newbold Comyn in Leamington Spa. It was a perfect size and available on Saturday 10th February so we could call it the Valentines Ball. Next was to tell people to save the date, organize the invitations, plan, and collect prizes for an auction and collect items for the raffle. John Wood (from LAM Action) very kindly designed the tickets, and formatted them, so that I could order them easily from Vistaprint, while friends and family were fantastic at sourcing auction and raffle prizes.

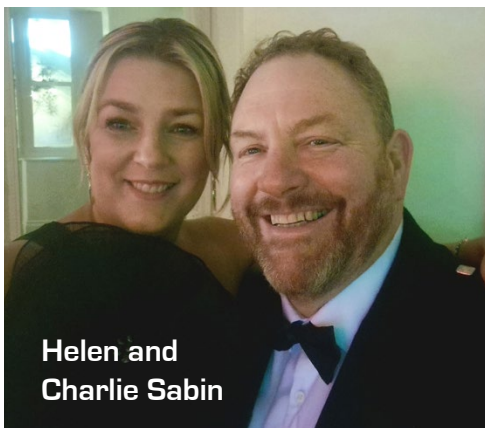
The tickets arrived very quickly, and we sold out within a week. (In hindsight we should have gone for a larger venue, we will do next time.) The only caveat with the venue was that the tables only sat up to 9 people. The stress of fitting friendship groups onto tables of 9 (most people were coming as couples) was a logistical nightmare until the venue said we could actually squeeze 10 per table as long as guests were happy with that! It was perfect as it also allowed us to add more guests.

Decorations bought, friends offering to help and an idea of a balloon arch in the shape of a heart ensured that it was all coming together.

I arrived at the venue on the morning of the ball to find friends and family already there waiting to help make the venue look as perfect as possible. A friend of Pinky's had offered to do the heart balloon arch for free and she set to as soon as the doors were unlocked. My son and his friend helped with table decorations while myself and others set up the tables for the auction and raffle prizes. Within 2 hours it was done! I was expecting to be there for a lot longer and am so grateful to all those that helped. Friendship is truly a valuable thing. I was able to head home for a rest before the big night!



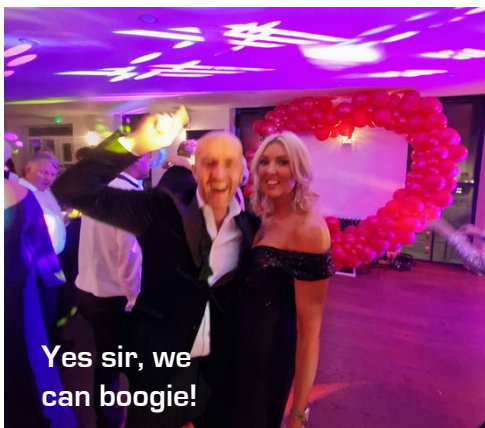
The lovely venue



Helen and Charlie Sabin



Selfie time



Yes sir, we can boogie!



And so can we!



Cheers!



Having a ball

I was delighted to get a request for 6 tickets from another LAM patient Georgia who was prepared to travel from Hertfordshire for the Ball. Then I got another request for 4 more from a friend of hers. How fantastic it is for us LAM patients to not only have the support of LAM Action, and other LAM patients but also our friends and family.

The evening was a huge success, bar the acoustics when my husband Charlie was trying to talk about LAM and conduct the auction! There was a lot of heckling from the Rugby Club tables! To be expected and always good fun!

We were lucky enough to book a fantastic Soul Singer, Sophia Soul, from Bedford who was very kindly paid for by Charlie so that we didn't eat into the profits. She was a huge success, if anyone ever comes across her make sure you attend one of her gigs if you like Soul music... to me she was the icing on the cake for the night.

We raised over £2500 and writing this article is a perfect opportunity to thank everyone for attending and spending their hard-earned cash. I also want to extend a special thanks to everyone that helped me organize such a fabulous event. I could not have done it without all the help and will be relying on them all again soon!

All that remains to be said is a special thanks and good luck to Eva and all the other runners raising vital funds for our incredible charity LAM Action.

Helen Sabin





London Marathon 2024 Preview

On Sunday 21st April thousands of runners will set off from Greenwich Park in London to take part in one of the world's oldest endurance events. Every year LAM Action secures charity places for the race and this year 7 of the runners taking on the 26 miles and 385 yards challenge will be there to raise funds for LAM Action.

Eva Sarginson is a primary school teacher from Leamington Spa and first fundraised for LAM Action when she took part in the British 10k in 2016. Now she is increasing the distance to support her mum. Eva said "This charity is very important to me because my mum, Helen, is a LAM patient herself, diagnosed in 2009. Despite being given a prognosis of only five years, fourteen years on my mum is still alive and kicking thanks to the amazing work of LAM Action to fund drug trials. I urge you to take a look at the wonderful things that LAM Action do. My training and completion of this marathon will undoubtedly be extremely tough, but it is just a small thanks in return for allowing me to have my mum longer than I ever thought." To support Eva's efforts go to:

<https://www.justgiving.com/page/eva-sarginson-1691343685302>

Jenny Hastings, a child protection officer from Cambridgeshire, was all set to run the marathon last year, but an injury the week before prevented her. LAM Action carried her place over so that, at last, Jenny can take part in the event she has trained so hard for. Jenny said “The lady I am running for is one of the strongest and most courageous people, and despite not being dealt the best hand in life she is so strong, passionate and kind. This is a truly awful disease with a massive impact on everyday quality of life.” To show your support for Jenny go to:

<https://2024tcslondonmarathon.enthuse.com/pf/jenny-hastings>

Leagh Callow is the manager of a livery yard near Taunton and is taking part for her aunt, Alex MacDonald. Leagh said, “I am running in the London Marathon 2024 to raise awareness and much needed funds for LAM Action. This charity is particularly close to me as my aunt is a LAM patient having been diagnosed with the condition in 2009. LAM Action was there to provide advice and support during a very anxious time for my aunt, who, like many other women when diagnosed with this rare disease, was unable to find any up to date or helpful information or support elsewhere. LAM Action is a crucial lifeline to LAM patients providing a vital link to other patients, health care professionals and supporting and funding critical research. This is my first time running in the London Marathon and I am really excited to take up the challenge to help raise funds and be part of the LAM Action team!” To support Leagh please go to:

<https://www.justgiving.com/page/leagh-callow-1695899761862>



Eva Sarginson



Jenny Hastings



Leagh Callow

Dr Justin Chu is an IVF Consultant at the Birmingham Women's Hospital – this will be his third marathon to raise funds for LAM Action. Justin said “LAM Action is very important to me as my wife, Anneke (who is also a doctor) was diagnosed with LAM in 2009. Initially she suffered with repeated pneumothoraces and required pleural surgery but since then she has completed her medical training and is now an Anaesthetic Consultant at the Hospital where she had her pleural surgery!! I hope to be able to raise money from family, friends and colleagues so that LAM Action can continue their great work.”

Anneke and their daughter, Lily (who is 10 this year) will be cheering for Justin on the day and if you would like to give his fundraising a boost here's the link:

<https://2024tcslondonmarathon.enthuse.com/pf/justin-chu>

Harry Read is 26 years old and works in the City of London as an investment analyst. He lives in south London and outside of running is keen on kick-boxing, playing golf and travelling. Harry volunteered to run for LAM Action because he's a friend of LAM Action chair, Leanne Lillywhite-Sutton. If you would like to help his fundraising please go to:

<https://2024tcslondonmarathon.enthuse.com/pf/harry-read>

Kevin Thomas is an accountant who was alerted to the possibility of running the marathon for LAM Action by his cousin. Kevin said, “I'll be running the London Marathon for LAM Action in support of my cousin Eleanor, who was diagnosed with the illness in 2016. Along with raising funds to support LAM Action directly, I've become increasingly aware of how important it is to raise awareness of LAM, so will be sharing her story as widely as possible. I live in London so will get to have a few practice runs on the course, and London will be my third marathon after Abu Dhabi and Eindhoven! Delighted to be part of the team for 2024!” Here's the link to support Kevin's fundraising:

<https://2024tcslondonmarathon.enthuse.com/pf/kevin-thomas-88589>

Paula Snee is a logistics manager from Brighouse, Yorkshire who has taken part in park runs, 10Ks and half marathons. She was lucky enough to win a place for her first marathon through the ballot. Paula chose to raise money for LAM Action because of a friend and said, “I have witnessed the challenges faced by one of my close friends, Sabah, who was diagnosed with LAM in 2023. This marathon is not just a race for me; it’s an opportunity to make a difference. Every step I take is aimed at raising awareness and funds to support LAM Action’s mission.” To help Paula in that goal please go to:

<https://2024tcslondonmarathon.enthuse.com/pf/paula-snee>

A number of LAM Action supporters will be along the route for the event and ready to greet the runners at the finish. It’s a great spectacle, so if you live near London your cheers of support will be much appreciated. Let us know where you plan to be and we will tell the runners to look out for you.

David Mercer



Justin Chu & Family



Harry Read



Kevin Thomas & Eleanor



Paula Snee



Ho Ho Horsey Christmas!

Last December, a Christmas Fun Day was kindly hosted by the Callow family at the Netherclay Livery Centre in Taunton, Somerset.

The day was held for family and friends of Netherclay Liveries to support my niece Leigh Callow, who is taking part in the upcoming London Marathon in April, to raise funds for LAM Action.

Riders and helpers turned out to enjoy an entertaining day of Christmas themed show-jumping, fun games, a bake-off competition, and prize raffle.

Masterchef Simon Callow served up burgers and mince pies, along with mulled wine (much appreciated on a cold winter weekend!).

Everyone contributed to the day and donated some fabulous prizes for the jump classes and raffle, with a good entry of tasty bakes too for everyone to sample. During the day helpers put up the jumps and cheered on the riders, even little Albie Callow wanted to get involved too with measuring jumps correctly!

Following a fun and competitive afternoon, rosettes and prizes were awarded and the winner of the bake-off announced, all

entries having been eagerly consumed! A great day was had by all and a fantastic **£550** was raised on the day, adding to a whopping £1700 already raised to date.

Thank you everyone and especially the Callows for hosting a super event!

Alex McDonald



Leagh
Callow



Albie Callow
measuring up



Alex McDonald
lending a hand



Team
Callow



Handing out
the prizes





Travel Insurance with pre-existing conditions

It's been quite a few years now since Clare Lauwerys wrote an excellent article for us about Travel Insurance, which has proved hugely useful to lots of our readers in the intervening time.

Travel Insurance with pre-existing conditions is always a very popular topic both on LAMLine and LAM Talk so it might be worth having a look at the link below, which will take you to a very useful article published by Martin Lewis on his Money Saving Expert website*:

<https://www.moneysavingexpert.com/insurance/pre-existing-travel-insurance/>

**Independent information not checked or verified by LAM Action*



Celebrating with Jan and Simon Johnson

20th Anniversary of my Lung Transplant

11 February 2024 marked a significant milestone for me: **20 years** since I received the single lung transplant that saved my life. So, on a wild Edinburgh day, my husband Peter and I hosted a champagne afternoon tea, to celebrate the anniversary and to thank the family and friends who have supported me through every step of my health journey.

One of the guests was my friend Susie. Our relationship is most unusual; she received the heart from the same donor as me. We were all thinking of our donor and her family as we toasted 40 extra years of life between us.

I was also thrilled that Simon and Jan Johnson were able to come to the party, because they both have played such an important part in my life ever since the LAM Trust, out of which LAM Action grew, was formed in 1997. Anne Tattersfield would also have been at the party, had she not been suffering from mobility problems. These three people have been driving research into LAM and providing information to women with LAM over the last three decades now, and I owe them huge thanks for their work – and their friendship.

Over that time, the progress made in LAM is astounding, especially given how rare LAM is and the relatively short timeframe. When I had my first lung collapses in 1987,

aged 22, after returning home from a month trekking in the Himalaya, the medics were not too concerned. I was young, fit and had been at extreme altitude so, after a partial pleurectomy, they sent me on my way without any diagnosis.

It was another five years before I got the diagnosis of lymphangiomyomatosis after a CT scan, bronchoscopy, and open lung biopsy. (The condition only became widely known as LAM a few years later.) In those pre-internet days, it was months before I found any reference to it, a dispiriting single-line entry in a textbook. With - at that time - no treatment, no cure and scant information, my prognosis was bleak and the diagnosis bewildering. Over the next few years, the disease progressed slowly but resolutely.

I obviously presented with LAM too early to benefit from the discovery of sirolimus as an effective treatment for LAM (in 2010), and the establishment of the National Centre for LAM in Nottingham as a place of best practice in the management of LAM patients (in 2011). However, I have relished seeing all the positive developments in LAM research and patient care. I have also been very lucky to benefit from advances in lung transplantation during my lifetime.



Gill and her
husband Peter

When I had my first lung collapses in 1987, lung transplants did not exist. When I received my formal diagnosis of LAM in 1992, the first successful ones were only just being performed. It was only in the mid-1990s, after further lung collapses and pleurodesis surgeries, that I was told that I might be a candidate for lung transplantation. And that gave me that very precious thing: hope.

Eventually, I received a single lung transplant at the Freeman Hospital in Newcastle in 2004. I've been celebrating life ever since. I still think it's a miracle.

Gill Hollis



Gill with Susie,
who received the
heart from the
same donor on 11
February 2004

The next edition of LAMPost will be out in the summer with a deadline for submissions of **August 20th** - thank you!

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