

AUGUST 2021

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



A Very Long Trip to the Beach

From the Editor's Desk



Welcome to the Summer 2021 edition of LAMPost, and while it has been mostly a bit of a damp squib of a summer so far, with only a few notable days of warm sunshine, we hope this edition of the newsletter will brighten your day.

As things slowly return to some sort of normality, one of the major tasks that has been occupying roughly half of the LAM Action Committee is the revamp of the LAM Action website. The current website has served us very well since 2013, though we are now working with our web development partners Framework Digital to bring the new site up to date and making it more accessible from mobile devices and also improving the user experience. If things go to plan we are hoping to relaunch the new site in the Autumn, so please stand by for further news.

I am delighted to be joined temporarily in editorial duties by my daughter, Lucy. You can read about Lucy's recent fundraising for LAM Action on the following pages, which was part of her Duke of Edinburgh Bronze award, and as she continues to work towards her award she has further volunteered her time to help the charity by assisting with the production of the newsletter.

Everyone at LAM Action sends hearty congratulations to Gill and David Tate on their recent marriage in Berkhamsted in July. Gill is a long-standing supporter of LAM Action and has helped out at various fundraisers in the past. As part of their wedding list, Gill and David asked for donations to LAM Action which raised a very generous £380 for the charity. Best wishes from us all for your future life together! ❤️ 💜



We hope you will enjoy this edition of LAMPPost, which includes what is perhaps a first for us with the publication of a work of fiction in the form of an intriguing short story, written by the very talented Sandra Grantham.

We hope to be back again in early December, with a publication deadline of November 27th, please email any articles or other contributions to: lampost@office.lamaction.org.

Until then please stay safe and well. Best wishes,

John, Francesca and Lucy

A Goodbye Message from Sharon

Dear Jill, LAM Trustees and LAM Action supporters,

Thank you so much for your cards and lovely messages including the very moving emails sent in by the LAM community. It is so kind of you all to take the trouble to write, it means the world to me.

It has been quite a week – well month!

I have been on a roller coaster ride of emotions as I prepared to leave my wonderful job having made the difficult decision to hang up my pulse oximeter!

Working in Simon's team with such wonderful and inspiring people - colleagues, patients and their families and friends, has been a great experience. I feel very fortunate indeed to have been part of the LAM world and to have cared for so many special people.

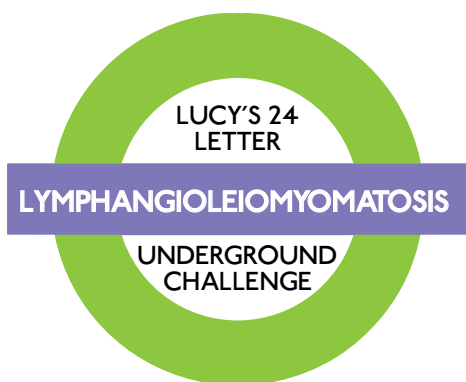
We have been through some good and bad times together and I am truly inspired by the courage and strength that I have witnessed over the years.

Thank you again for all the support that LAM Action has given both to me and to the service, resulting in the development of such a joyful and effective partnership.

Wishing you all the very best for the future, with warm regards,

Sharon Fuller (Old LAM Nurse!!)





Tuesday June 1st

In aid of

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Hi, I'm Lucy and on Tuesday 1st June I completed a fundraiser for LAM Action where I visited ten different stations which have all the letters to spell lymphangioleiomyomatosis. I set off with my dad to accompany me at 10am, had a lunch break at McDonalds and arrived back at home at around 5pm.

I started off at Kensington Olympia (collecting LYMP) but the District Line wasn't running that day so at the very first hurdle I had to change my carefully laid plans and get on the overground service instead. I had to get off the train, take a photo of the roundel and get back on the train all before the doors closed again! We then carried on to Hanger Lane (collecting HANG), Willesden Junction (IO), had the lunch break at Leicester Square (collecting LEI), Ealing Common (OM), Ealing Broadway (Y), West Brompton (OM), Stratford (AT) Charing Cross (OS) and finished at Highbury and Islington (collecting IS).

I did this fundraiser for my Bronze DofE award under the volunteering section. The award consists of doing 3-6 months of work for the skills, physical and volunteering sections. There is also a two-day expedition to complete. So far, I have raised over £1000 for LAM Action which I am very happy about and very thankful to everyone who has donated to help ladies like my mum who have LAM. Big thanks also to Jo Pisani for agreeing to be my mentor and giving up her time to help me with preparing for the fundraiser.

Lucy Wood





Art for LAM Action's Sake

Joan Mensor has been using her artistic skills to raise both funds for LAM Action and also to raise awareness of the condition. LAMPPost readers may recall Joan from the Winter 2019 edition where, by way of introduction, she wrote one her deliciously dotty 'nonsense poems' about the 'Old Lady from Lancing'.

Joan has now moved from Lancing on the south coast to the midlands to be nearer her family and when she heard about the Captain Tom 100 Challenge earlier this year, she decided to put her artistic skills to good use to create 100 unique hand-made cards which she could send to friends and family in return for donations to LAM Action.

Since moving, Joan has continued to make her cards and has found a new outlet for them. We are also very happy to hear that Joan continues to write her nonsense poems, and a couple of them are reproduced below.

"I don't actually do straightforward painting now, but more abstract collages. The community local library in Burton Latimer which is where I live has taken in a box of my cards for people to help themselves and have now arranged for me to use some of their space to work at the cards in whenever I feel able to. A resident pop up artist you might say, where I can talk to people about LAM and the therapeutic value of creative activities (another lifelong passion of mine). This little village is very community minded, and I love it. Being

by the sea was lovely but became somewhat frustrating as I was no longer able to beach-comb. Now I am in the countryside, which is just as inspiring work wise, especially being surrounded by trees.

I am going to write out a nonsense poem for you about tree hugging, and I had thought that other Lammies might relate to it. Every time I have a lung function test, I think to myself that with the gas exchange problem I have my own little climate change problem going on inside me! But it has given me a deeper empathy with trees and how we have undervalued them.

*In Borem Wood lived Theresa Green
who loved to hug trees and could often be seen
at the local park, arms wrapped round her big friends,
folk thought her barking mad, and completely round the bend,
but how less boring Borem Wood would seem
if all had the pleasure of our Theresa Green!*



The artist in
her studio!

Here's another one which, although about technology, came from feeling the fear which grabs people when facing new changes in their lives, whatever, especially apparent in these pandemic days. We moved between lockdowns last year, and friends were amazed, but, although it wasn't easy, I knew it was right and it has proved so. It did entail a lot of form filling by email, which I hated but learnt through it, and now, here I am with my own iPad!

Love What You Fear

*It follows me here, it follows me there,
Technology follows me everywhere.
It haunts me, it taunts me
It tells me I'm a fool,
But now I'll take it no longer
Cos actually I think I'm quite cool!
So I've told it I love it's potential
That I'm inviting it in as a friend,
And no longer is it a monster
That is driving me quite round the bend,
I've faced it, embraced it,
And let love dispel any fear
For I know it's only a part of me,
And I love me to bits, so there! :-)*

Another benefit of being here in the midlands is being closer to Nottingham. Kindly, Prof. Johnson has agreed to see me in October, and I am hoping he will give me advice which will keep me going a while longer, as I have some exciting artwork to do."

Joan Mensor





A 700km Ride Across Poland for Nathalie

On 31st May 2021 Peter Los set out with 5 of his friends to ride on horseback from Komarno in the south of Poland to the Nowecin, on the Baltic coast in the north. The epic ride of 700km took place in memory of Peter's wife Nathalie Los, who had LAM. After a brave 10 year battle with the condition, Nathalie died on 1st November 2019 - she was 51 years old.

Our original idea was to take 30 days to complete the 700km ride from the south of Poland to the north of Poland. However, due to work commitments, we couldn't take more than three weeks holiday, so we had to adjust the challenging trip to 17 days. For the first week, we rode for 4 days with 1-day rest, second week we rode for 5 days with 1day rest, and for the final week, we rode for 6 consecutive days. Each day we set a target to ride 35km, but one day we exceeded this and rode for 58km!

At the start, it was challenging for the horses and us and there was a lot of uncertainty what could happen. Over time, Rüdiger managed to master the GPS and set better routes as they days went on. We had a lot of obstacles to overcome during our journey, for example, motorways, towns, rivers, railway tracks. All these factors sometimes

made our journey longer having to find a way to pass, where on some days we spent 10 long hours in the saddle. On the road, we met many people who stopped to ask where we were going and where we were from. Many people were so surprised that we were taking such a trip across Poland by horse! Not many people in Poland have heard of LAM so it was a good opportunity to raise awareness and tell my story during our journey. One day we stopped to give water to the horses in a remote village that we were passing, we were so taken aback by the people's kindness and generosity of inviting us to their house for a barbecue dinner.



I never had doubts that I would not finish the journey, however my biggest worry was that my horse Grom would not make it. In the end, I think Grom was in better shape than I was! One evening we were sitting outside this unique B&B, where we saw a peacock named Pawel who lived in a tree. Every evening, at nine o'clock, he would climb the tree. It provided some humour since this was something we have not seen before.

We had a support vehicle with us, which was very useful in the end. Halfway through the journey, one of the horses couldn't go on any longer, so we needed to transport the horse back to the stables that we were renting from. We were a team of six people with very different characters, but luckily when we got into a few tricky situations we all calmly got together to sort it out.

One of the highlights of the LAM Action Annual Meeting on Saturday June 12th was the live link up between Peter and the team and David Mercer in the studio. Thanks to the miracle of modern technology we were all able to see and hear Peter give us an update on their progress literally from the middle of a forest in Poland, and it was a very inspiring and quite emotional moment for everybody tuning in.



We travelled through large forests and wilderness, but luckily the only wild animals we saw were big, beautiful birds like Heron, Stork, Red Kite and Crane. I would do this epic journey again, but it would need some funding, because it was very expensive to co-ordinate the logistics and to participate. I am very happy that I was able to contribute to such a great cause by taking this journey and hopefully bringing more awareness of LAM, which sadly took Nathalie away.

Peter Los

Journey's end - the team were joined by some friends from the nearby stables for a well-deserved paddle in the Baltic Sea



LAM Action would like to say a huge thank you to Peter and all his team for taking on such an epic challenge in order to raise some valuable funds and also awareness of the condition - well done everybody, dziekuje bardzo! If you have been moved or inspired by Peter's story there is still time to help the team to get nearer to their fundraising target by visiting:

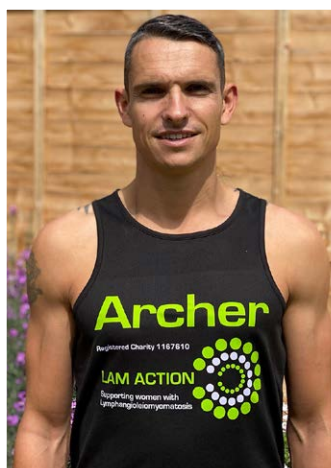
<https://www.justgiving.com/fundraising/lamteamtour2021>





After a Marathon Wait, it's Finally Here

It has been a very frustrating 18 months for LAM Action's marathon runners, due to the postponement of last year's event, but they are now back on track and raring to go again. Sadly Matt Thomas has had to withdraw through injury, but he is hoping to be back for the 2022 event. We also have one new runner, Tom Archer, for this year's race which will take place on Sunday October 3rd.



Tom Archer from Aldridge, Walsall, is an army veteran who will be running the London Marathon to support family friend and LAM Action Chair Leanne Lillywhite-Sutton. A former Grenadier Guard and member of the 3rd Battalion, Parachute Regiment, Tom was used to having superior levels of fitness, but after leaving the army, that all changed, and he admits that he could barely run a mile.

The chance to raise some funds for LAM Action and to support Leanne and other women in the UK who also suffer from the condition has spurred him on to regain his former levels of fitness and he is hoping to complete the course in under 3 hours. If you would like to support Tom's fundraising, please visit his page at:

www.justgiving.com/fundraising/tom-archer3



Readers of LAMPPost will need no introduction to **Lucas Meagor**, who will be pounding the streets of the capital for the 4th time in support of LAM Action, having also completed the Virtual London Marathon last year running around the streets of Kingston Upon Hull, so this will be the 5th time in total that Lucas has represented us.

Lucas's connection to the charity is through his good friend Alex McDonald and he was famously interviewed live on the BBC en route around the course in 2013 when he ran in his London Olympics Games Maker outfit.

Lucas, originally from Frome in Somerset, now lives in Kingston Upon Hull, and in 2017 ran the marathon as a phone box, more specifically a KCOM cream coloured phone box, which are unique to the city. This year he will be re-attempting to get the Guinness World Record in a new look phone box, designed by his friend, Martin Beaumont, and produced locally by Scribes Digital Printing, with thanks to MKM Building Supplies for the frame.

Good luck Lucas and we look forward to seeing your lovely new phone box come whizzing past on October 3rd! If you would like to help Lucas reach his fundraising target for LAM Action, please visit his page at:
www.virginmoneygiving.com/LKR2021



Nicki Curwood and **Rachel Stinton** will also be familiar to our readers having completed the Virtual London Marathon last year, and they will be running again in support of their friend and former LAM Action Committee Member Helen Sabin.

“Finally the countdown is real! After a long period of what feels like forever marathon training, we are finally believing that the London Marathon is going to take place and we are going to be a part of it!

Our training has been on and off as you can imagine, but despite the lockdown periods, we followed the guidance and were able to continue running and keep our fitness levels up. We took part in the virtual marathon last year and were able to run with a group of friends, celebrating that we could run together in a small group and continuing to fundraise where we could.

Despite on/off injuries and the odd illness knocking us back, we have been able to put that behind us and focus on supporting LAM Action and finally being able to accomplish what we set out to do! Big thanks to the charity for supporting the delay in the marathon and of course to our friends and family who have kept smiling as we disappear off on yet another long run!

Thanks all – see you at the finish line!

Nicki & Rachel xx”

<https://uk.virginmoneygiving.com/Team/NickiandRachel>



Good luck to all of our lovely runners who will be taking part in the London Marathon on **Sunday October 3rd** to raise valuable funds for LAM Action!

Please come down on the day and cheer them on if you are able to, it is always an amazing experience and our runners will really appreciate every bit of support you can give them.





Still Life by Sandra Grantham

The rest of the passengers who'd travelled the whole way, were standing ready to leap off the train when it stopped at the end of the line. Pearl Dott was left behind as usual, as they strode along the platform and up the steps to the booking hall, vanishing before she had gathered herself together. These days she was unable to keep up with normal pace, although it didn't particularly bother her. The stairs slowed her further and by the time she reached the exit, there was no one in sight. The cheerless forecourt was empty.

Pearl seemed a lonely figure, stopping to catch her breath outside the deeply suburban west London station. But she was busy scrutinizing a building on the other side of the road, unaware of the impression she made. A sharp wind blew hair across her face as she rewound her scarf with a shiver.

She hadn't visited this neighbourhood for years and the scenery had changed. Most obvious was the disappearance of the trees, no doubt victim to a developer's chainsaw. She always noticed trees. She had no idea why, as she'd been born and bred in London, or maybe that was why. Trees in central London were prized and largely protected.

Across the road under a nondescript sky, the new

three-storey façade receiving her attention was laced with narrow windows. They gave little away. A large numeral, cast in the concrete of the entrance, confirmed the address. But Pearl hesitated. Now she had come this far, she was beset with doubts and questioned herself constantly. She had lived with a knot of uncertainty in her head for too long. It blocked the space meant for clear reasoning, which in turn, had set her on this course of action or plan or whatever it was. She was nervous.

Although the station behind her was deserted, a constant stream of vehicles was passing along the road in front. Waiting for a break in the traffic, she pulled her bag higher up her shoulder, slipped her cold hands into her pockets and stepped out across the road, carelessly turning her ankle on the kerb. She told herself to relax as she threaded her way through a slow-moving taxi rank and stopped at the revolving doors leading into the building. Once inside, she checked the list of offices and took an empty lift to the first floor, where she found a receptionist, gave her name and appointment time, and sat by a window to wait. Through the narrow window she watched the traffic below without questioning herself further.

Minutes later, a woman called out her name. It wasn't the first time Pearl had been to see a therapist, but it was the first time she had visited Lydia Wells. She hoped this would be a helpful meeting, but knowing the danger of not being able to stop talking once she started, she planned to keep fairly quiet, initially at least.

Lydia Wells' eyes widened as she introduced herself, while guiding Pearl toward her office. The surprise was mutual, as they glanced briefly at each other and looked away. Had they met before? They were instantly aware of being physically similar. They had the same thick, dark grey hair, face colour and height. Though Pearl thought that she was probably the elder of the two.

She cast her eyes round the room as she sat down, taken aback by its antithesis to the encompassing modern building. An old Middle Eastern rug covered most of the floor, with two large Edwardian armchairs placed at angles in the centre. A row of primitive painted-clay figurines paraded along one side of a desk, which was set against a wall covered with overloaded bookshelves. On the floor under the window was what looked like a Hans Coper bowl, placed to collect the light falling beneath a half-pulled blind, forming a singular still life.

‘Where would you like to begin?’ Lydia Wells asked with a slight transatlantic accent, as she made herself comfortable opposite Pearl.

‘Do you want to tell me a little about yourself, or explain how you think I might help? It’s up to you, take your time.’ She sat forward, put her elbows on the arms of the chair and linked her hands together in her lap. To Pearl she seemed gentle, but a bit prickly.

Pearl smiled, ‘it’s not easy to explain, though I suppose it never is by the time a person needs to come here.’ She faltered, trying to find the right words, ‘I lost part of myself twenty years ago.’

‘That’s quite specific. Did something particular happen to cause you to feel that?’

‘But it’s as though what I lost is still with me,’ Pearl continued, ignoring the question.

‘It does sound like a riddle you need help to solve.’

Pearl sat in silence, furtively counting on her fingers, as though to pace herself before speaking again. She also wanted to be sure to describe her feelings objectively.

‘I fell in love, which made me reckless and conceited. Love seems to do that. I thought it was mutual, though in hindsight I think that’s very unlikely.’

‘But at the time you thought it was something you shared?’

‘Yes, I did,’ Pearl shrugged.

Lydia looked up and stared at Pearl as though trying to gauge the reason for her hesitancy. Her need to talk appeared to be battling with her diffidence.

‘Can you explain more. Were you together very long?’

‘We were both already married, unhappily married, but we began to live together about a month after we met. It was a heady time. Then we set up a company between us. Well, it was mine mostly.’

‘That sounds risky, but certainly committed. Why do you question his mutual feelings for you?’ Lydia sat back in her chair watching Pearl cope with her obvious discomfort.

‘After ten years together, we got married. We both had a young child from our previous marriages. They were nearly the same age and we made an instant family. Our children were happy.’

Lydia found it hard to conceal her surprise; it wasn’t what she had expected to hear. She watched Pearl take a breath and slowly exhale.

‘But just a year after we married he vanished without a word, taking part of me with him and breaking my heart. He also took his daughter, of course. There was no particular argument and we have never spoken to each other about it. I had to invent reasons to make it make sense. I mostly blamed myself. We’ve had no contact for years.’

Lydia Wells sat very still, looking down at her hands. After a while she asked,

‘So you’ve had little or no closure?’

Pearl shook her head.

‘Not long after we moved in together I had a collapsed

lung and spent time in hospital. It slowly got better, but the doctors couldn't explain why it had happened. During the following years it affected my strength and made running the business difficult, which he found harder to deal with than I, and by the time we were married my breathing was a problem and I had started having tests to find out what was wrong.

'That was when he left. I pleaded with his family, but they wouldn't tell me where he was. Said they didn't know.

'I was so shocked. I assumed he was my closest friend and had begun to rely on him for support. I searched the house looking for clues and found a roll of unpaid bills and bank statements hidden in the cellar, dating back some months. Our bank account was virtually empty and nothing had been paid, not even the mortgage. He'd obviously been planning his move for some time and I'd been completely unaware. I felt such an idiot. A few days later, bailiffs came to the house.'

Pearl's eyes settled on the bowl of glittering light. Lydia sighed and shifted in her seat but said nothing. Eventually Pearl stirred herself.

'I went to see the specialist to get the test results, four weeks after he'd disappeared. He found out about the appointment and turned up at the hospital waiting room, I was delighted to see him. I thought he was coming home. But he told me he was living with an old friend of mine and that she had insisted he should come and let me know. My head exploded, I felt like I was going mad, but he knew I wouldn't embarrass him in public.

'After quietly begging me to sell our house, saying he was penniless, he left again. When the specialist told me I had an untreatable lung disease and would probably die within five years, I hardly registered the news and cared even less.'

Lydia sat quietly looking at Pearl through another

long silence till eventually she spoke.

‘But you survived, you’re here twenty years after that.’

‘I did. With the help of good friends, state assistance and luck, my son and I survived. The divorce took over three years and became acrimonious. Then my solicitor proved that he had committed perjury and he lost his battle to claim the house. The case had gone to the High Court by then and the judge dismissed it. I was allowed to keep our home and I didn’t feel guilty, because he’d already bought another house with my ex-friend.

‘During those years my son and I worked hard. I managed to get a grant to go to an Art College and take a degree to make myself employable, and at the same time my son won a scholarship to a great university. I missed him when he went away, so work became a compulsion and it also stopped me dwelling on my diagnosis and divorce. After taking the degree, I found funding to cover research for a doctorate for four more years. I was scared that if I stopped work there would be too much time to think. Eventually, I got a good job in a large museum.

‘We did better than survive, but a core of hurt has also survived in my head, and I still miss my stepdaughter, even though she had developed into a difficult teenager.’

Lydia stood up and offered Pearl a glass of water. Then, taking a glass herself, she sat back down and looked at her watch,

‘I can manage another half hour, if that’s any good? I feel you have something more to tell me?’

Pearl nodded and took a large gulp of water before continuing.

‘I heard later that he treated my ex-friend in much the same way, although she managed to keep hold of her money, which was good because she had quite a lot.’

She braced herself, then said,

‘He’s married again now.’

‘How do you know?’

‘He told me. Before I started my research, I was given a year’s fellowship to work in a Manhattan museum. I had no idea he was in New York, but he somehow discovered I was there. He was staying with a friend and insisted on coming to the museum to see me. But what he really wanted was to tell me his plans, that he was marrying this American friend that he had often spoken about, and that she had insisted he should come and tell me - déjà vu.

‘He also said she was now a qualified therapist and was helping him sort out his life.’

When Pearl raised her eyes to look at Lydia, she wasn’t surprised by the expression on her face. Lydia had noticeably paled.

‘You’re talking about my husband, aren’t you?’

‘I am. Yes.’

Pearl no longer felt scared by what she was doing, because she could already feel the knot untying in her head like flowers blooming. It was selfish, but it felt good and she didn’t want to stop. Pearl had never been able to talk to her ex-husband, but now she could speak to a messenger.

‘A friend of mine who lives near you, told me you had both moved back to his old home, close to his family, so it wasn’t hard to trace your practice. I’m sorry.’

Pearl was unable read the look on Lydia’s face. She didn’t want to distress her further, but needed to explain a little more.

‘I think you knew his first wife. I didn’t. It took me some time to discover that she was mentally ill, and when I did, I was stunned to find that he had abandoned her. He had told me a different story.

'In her confused state she would sometimes search for her husband and daughter, and the other 'lost children' of her muddled imagination. She would discover where we were living and then write or phone, usually while she was under medication therapy having been sectioned during a police intervention. Unfortunately she had to speak to me, though she didn't acknowledge my existence, because he refused to talk to her.

'She arrived out of the blue one time, to see her daughter. The desperate state she was in was so awful and visible, that she frightened her. The poor little girl hid away in her room and begged me to let her stay there. It was so painful. I wanted to help this desperate woman; I was haunted by her, but felt it more important to protect her daughter.'

'That was the reason it took so many years before we got married, he was scared of facing his wife in a divorce court, of acknowledging her frailty and of possibly being asked to support her. We have all caused so much heartache.'

The two women looked at each other. Pearl uncrossed her legs and sat forward, ready to leave.

'Diseased lungs have stopped me working, so I have too much time to think. I'm happily married now, and I no longer want these memories to pursue me. Speaking to you has been like an exorcism. I'm sorry I had to do it, but thank you for listening.'

A frown crossed Lydia's face, and then she nodded and stood up. She paced to the door and held it open without a word. And without a word, Pearl Dott walked out.

The next edition of LAMPost will be out in December 2021 with a deadline for submissions of **November 27** - thank you!

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