

MAY 2022

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Burton Latimer
Community Managed Library

LibraryPlus



Send in the Clowns!

From the Editor's Desk



Spring is now well and truly here, with lighter evenings and better, warmer weather, a time for shedding winter coats and venturing outside for some (hopefully) fresh air, though with the constant reminder about the 'C Word' which is still lurking around like an unwanted guest. Indeed, if you read the press these days, the pandemic and ongoing **COVID-19** situation have been well and truly relegated to the inside pages - while there are of course other important events unfolding on the world stage it would seem that to all intents and purposes, it is now all over. Yet just a couple of weeks ago 1 in 12 people in England were infected with **COVID-19** so it is still worrying times for people with underlying conditions, and the majority of us will have either had the virus or know a close friend or family member who has contracted it. Professor Simon Johnson has shared the results of an international survey of **COVID-19** in women with **LAM**, and you can read a summary on the following pages.

Followers of our Facebook pages will have seen that LAM Action is celebrating its 'Silver Jubilee' in 2022, marking 25 years since the first origins of a patient organisation when the LAM Trust was established back in 1997. We are planning to celebrate the occasion during our 2022 Annual Meeting which will take place virtually on **Saturday June 11th**. We are still working on the agenda and timings but it is shaping up to be a really interesting meeting which we hope you will be able to watch and enjoy - full details to follow.

You will also be able to get involved in the 25 year celebrations by taking part in the '**25 Challenge**', and you can read all about how you can help us celebrate while raising some valuable funds in doing so below.

There have been a few recent changes to the LAM Action Committee and very sadly we say goodbye to **Professor Anne Tattersfield** and also to **Heather Mills**. Anne has been synonymous with both LAM and LAM Action since the very early days, providing not only expert medical knowledge but also the calm and steady voice of experience, as well as being one of the movers and shakers behind the formation of the charity. Heather also provided invaluable support to the committee on various initiatives - just saying 'thank you' to them both feels extremely inadequate and they will both be greatly missed.

Harriet Saunders has now joined the Committee and we are also hoping to welcome one other new recruit very soon, you can find out more about Harriet and her life with LAM on the following pages.

We will hope to be back again towards the end of the Summer, with a publication deadline of July 30th, please email any articles or other contributions to: lampost@office.lamaction.org.

Until then please stay safe and well, and we hope you have a lovely summer.

John and Francesca

Celebrate 25 Years of LAM Action with the 25 Challenge!



This year LAM Action celebrates 25 years of supporting women with LAM and raising funds for research. In that time the charity has raised nearly £1.5 million and funded a full-time researcher along with PhD students and clinical trials. In the run-up to celebrations of the 25th anniversary at LAM Action's Virtual Meeting on 11 June we are launching the 25 Challenge and we are asking the LAM community to get involved. Throughout May we would like you, your families and your friends to take part in an activity of your choice based around the number 25 and fundraise or donate to support LAM Action.

The 25 Challenge is open to all ages and the ideas and options are endless! Whether you run for 25 miles or just walk 25 times round your garden, juggle for 25 minutes or play the piano for 2.5 hours, bake 25 cupcakes or sit in icy water for 25 seconds – your support for LAM Action will be invaluable at the end of a difficult couple of years.

Click here to fundraise/donate for LAM Action:

www.justgiving.com/lamaction

and please send news and pictures of your events to david.mercer@office.lamaction.org

Introducing Harriet Saunders

The LAM Action Committee are delighted to welcome Harriet Saunders as the latest addition to the list of Trustees for the charity. By way of introduction, Harriet has written the following biography, as well as a piece detailing her life living with LAM which you can find further on.



Hi everybody, my name is Harriet Saunders. I am 27, engaged to be married to my partner Adam next February and I am a patient living with LAM.

I am currently working full time as a Genetic Technologist at the West Midlands Regional Genetics Laboratory in Birmingham, and I have a BSc in Human Biosciences and an MSc in Prenatal Genetics and Fetal Medicine. I plan on eventually becoming a Clinical Scientist however I am still enjoying my time working in a lab at the moment.

I have an extremely active and hectic life, in a good way! I love music (including festivals and gigs), socialising with friends, sports and gym, going on weekends and trips away, science, TV, and life in general! I am determined to be as positive as I can since my LAM diagnosis and especially reassuring newly diagnosed patients that life is not always doom and gloom living with LAM.

I was diagnosed with LAM in April 2019 after presenting with a pneumothorax which subsequently led to a bullectomy and pleurectomy. I did however get diagnosed with angiomyolipomas (which were embolized) in 2012. After this I was discharged from hospital, but I did not have any further investigations, so I did not know I had LAM at the time. I was always thought to have asthma

as a teenager, but I truly don't believe I did as I didn't suffer with breathlessness or wheezing; I mainly just got very sick whenever I had a chest infection and most of the time I had to be nebulised.

I have had quite a few difficult years, as unfortunately my Dad passed away in 2013 with terminal oesophagus cancer, this wasn't thought to be hereditary and there are no known genetic conditions in my family. My immediate family are my older sister (30) who is just recently married, and my Mum, Mary (66). Although we have suffered a tragic loss of my Dad, myself, sister and Mum have become extremely close and we really get on so well and go on many trips away together and they also support me so much.

I have a brilliant life and although it is sometimes difficult to have LAM, it certainly does not rule my life. I am currently on Rapamycin 1mg, and I don't really get too many side effects, and it appears to be keeping my lungs and kidney tumours stable. I have also had COVID in January 2022 whilst being triple vaccinated, and it did not have any impact on my health which was wonderful! I stay fit, swim, gym and walks, I don't smoke, and I keep my mental health healthy.

My most recent achievement is going snowboarding at 3000m altitude in March 2022, and even though I was a little more breathless and tired than before, I still managed to carry out snowboarding whilst being at that high altitude (although this trip was aided with a few aperol spritzes in the apres ski!!). I am now training for a sprint triathlon in July which consists of a continuous 300m sea swim, 10km cycle and 2.5km run which will be a massive challenge for me (especially as I am not a natural swimmer!).

Although I sometimes struggle with anxiety, pains, medication side effects, I do my best to manage these and to keep as busy and active as possible. My partner, Adam, has been truly the most amazing person ever

in supporting me in everything I do. Always coming to hospital appointments, looking after me when I've needed it, and pushing me to do as much as possible. He will be assisting me with the sprint triathlon in July.

My life has changed since having LAM, not necessarily in a bad way, as I feel reassured having Professor Johnson to turn to, and he seems very confident in my lung function and blood results – I feel safe under his care. I also do a lot more and think about my physical fitness a lot more, and I always strive to be the best I can.

Although the future can be scary, I focus on all the positive things I have in my life and take each day as it comes. I truly hope I can help LAM Action and give contributions which make a positive difference to other patients and their families.

Harriet Saunders



International Survey of COVID-19 in Women with LAM

It is of little doubt that the last two years of the **COVID-19** pandemic have been a very worrying time for everybody, though particularly for those with lung conditions. Professor Simon Johnson has kindly taken the time to summarise the results of an international survey carried out on women with **LAM**, which will hopefully provide some reassurance.

An international group of **LAM** specialists conducted a survey of **LAM** clinics in the UK, Brazil, Europe, USA and Japan to study the impacts and outcomes of **COVID 19** infection in women with **LAM**.

We identified 91 women with **LAM** who contracted **COVID 19**. 77 had sporadic-**LAM** and 14 had **TSC-LAM**. Questions addressed were how severe infections in women with **LAM** were, what were the risk factors for severe infections, what was the effect of the main treatments for **LAM**, rapamycin and everolimus, on **COVID** infections and the longer-term outcomes of **COVID 19** in **LAM**.

COVID 19 infection in LAM. The patients affected had a range of disease severity with around half taking either rapamycin or everolimus. One fifth of patients needed

admission to hospital with an average hospital stay of eleven days. One patient with severe LAM of the 91 studied died from COVID 19.

LAM risk factors and severity. Patients with lower gas transfer measurements (DLCO) were more likely to need admission to hospital and oxygen treatment or an increase in their oxygen treatment.

Effect of rapamycin and everolimus on COVID 19. As expected, people taking rapamycin and everolimus tended to have lower lung function than patients who didn't need these drugs for their LAM. Allowing for differences in lung function, rapamycin and everolimus did not appear to make COVID infections more severe.

Long COVID and LAM. Around one fifth of patients had symptoms more than six weeks after infection (known as long COVID), the persisting symptoms were mostly fatigue and increased breathlessness. This is similar to patients without LAM after COVID 19 infection.

Results in context. The findings are fairly reassuring in that the outcomes for women with LAM were not very different from healthy individuals and rapamycin and everolimus do not make people more susceptible to severe infections. The project was conducted early in the pandemic with the original COVID strains and before vaccinations were available; meaning that the use of vaccines and newer treatments for COVID 19 will reduce the number of severe infections in the future.

You can read the full paper here:

<https://www.sciencedirect.com/science/article/pii/S001236922105166>

Professor Simon Johnson



Raising Funds for LAM Action in Memory of Justine

LAM Action has received a fantastic £5,000 donation in memory of Justine Laymond, thanks to Justine's partner Tom Hipperson, his colleagues and his employers, Gallagher Re. They turned a team night out to play 10-pin bowling into a charity fundraiser for LAM Action.

Tom's team described the event: "As we all know, Tom's wonderful other half, Justine, incredibly sadly passed away before Christmas.

In the true spirit of this great team we are all part of, we wanted to make a positive contribution to something to celebrate the fabulous and inspiring life of Justine, especially with all the physical adversity she faced along the way. Simply donating to Tom's chosen charity was not good enough for this team of fun-loving high achievers – so we have decided to add some fun and charitable competition into our night out."

They devised a scoring system that committed donations per pins knocked down, and also encouraged people to make additional donations. The event was a huge success, raising £2,500 on the night. Thanks to a "matched funding" programme offered by their employers, Gallagher Re

agreed to match the sum pound for pound, doubling the amount raised to £5,000. This itself will be augmented by Gift Aid.

As Tom says: “I am truly amazed at the generosity of my team members and thankful for the support of the company I work for, Gallagher Re. Even though the circumstances are incredibly sad, I hope that this in some way will mark the huge impact Justine had on our lives.”

Gill Hollis

Matched Giving – An easy way to multiply fundraising

Many large companies offer a “matched giving” programme (also known as “matched funding”), helping their employees to boost their charitable fundraising. It’s a simple concept: the employer agrees to match the money employees raise with a donation of their own. Some companies offer this on a pound-for-pound basis, while others will specify the amount they’re prepared to give.

Matched giving is a wonderful way of augmenting fundraising, and it enables companies to support charities that are meaningful to their employees.

So before you embark on any fundraising, it’s worth checking whether your employer – or the employer of a family member or friend - offer a matched giving programme. Usually the HR department will have details of charitable giving programmes.



The Only Way is Essex!

On the morning of Sunday 29th May around 25,000 cyclists will gather on the Victoria Embankment in London to take on a new 100 mile challenge, as Ride London heads into the lanes of Essex before finishing on Tower Bridge. LAM Action has 8 riders competing in the event:

Oliver W has a sister, Kate, who has LAM and lives in Perth, Australia. Oliver last took part in Ride London in 2015 when the route went through the Surrey Hills, now he is doing it again to raise funds in the search for a cure for LAM. Oliver is a compliance manager from Essex, so he will be on his home turf. He seems to have taken the 25 Challenge to heart because in May he is also stretching himself in these events: 8 May -42km walk; 15 May -12km obstacle race; 22 May – 20k run. All the funds he raises will go to LAM Action. If you would like to add to Oli's total please go to his fundraising page:

<https://www.justgiving.com/fundraising/4-x-4-challenge-may-2022>

Simon Fairbrother is a friend of Sally Merritt-Collins, one of the LAM Action Trustees, who has LAM. Simon is an engineer who lives in Bewdley, Worcestershire and has travelled to France and Italy to participate in long distance cycles, but this will be his first Ride London. To support Simon's fundraising visit:

www.justgiving.com/fundraising/simon-fairbrother2



Oliver W



Simon
Fairbrother

Yann Quелvennec lives in Devon and had hoped to ride for LAM Action in 2020, when Ride London was cancelled because of the pandemic. He will be recognizable in his LAM Action cycle shirt with 'La Frog' on his back. Yann's fundraising page is:

www.justgiving.com/fundraising/yann-quelvennec

Joanne Boardman is also from Devon, where she works as a fitness co-ordinator. Jo cycled from John O'Groats to Lands End in 7 days, so London to Essex and back should be achievable for her. To support Jo's fundraising please visit:

<https://ridelondon.enthuse.com/pf/joanne-boardman>



Yann
Quелvennec



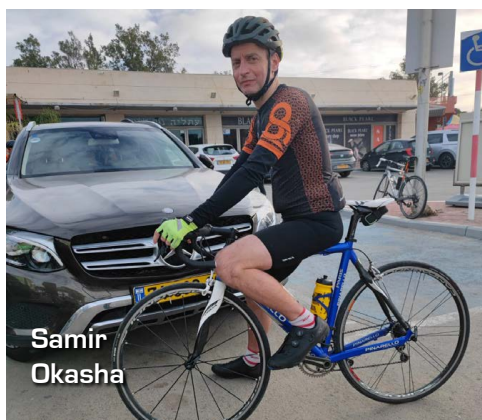
Jo Boardman

Samir Okasha is a lecturer at Bristol University and married to Havi Carel, who has LAM. Samir is a keen club cyclist who has taken part in other 100 mile events, but this will be his first Ride London. Samir's fundraising page is:

www.justgiving.com/fundraising/havi-carel

Andrew Barham has completed Ride London twice before. He's a property manager from Twickenham, in West London and he's hoping to raise money through family and friends. If you'd like to widen his reach go to:

www.justgiving.com/fundraising/andrewbarham2



Samir
Okasha



Andrew
Barham

Jo Pisani and **John Brownridge** are a couple taking on the 100 mile challenge. They have been cycling together for the last 25 years. They enjoy cycle touring and have been to Cuba, Italy, France and Sweden on bikes. They spent their honeymoon cycling between Bangkok and Ho Chi Minh City.

John is a keen cyclist and loves long distance rides. He completed John o' Groats to Lands End solo 12 years ago. The Essex 100 is personally significant for him since it passes two of his schools, the hospital he was born in and close to his childhood home.

Jo is a trustee of LAM Action and a LAM patient. She works with several medical charities and is impressed by the way in which LAM Action's fundraising is used directly to support patients and their families and to further LAM research. Jo added, "Don't expect us to break any records on this event. We do like to stop for coffee and to enjoy the views!" To support Jo and John's fundraising go to:

<https://www.justgiving.com/fundraising/jo-pisani6>



Jo Pisani



John Brownridge

Here's a map of the route – if you live nearby and want to support the LAM Action team – every cheer will help them get closer to their finish line.

David Mercer





Joan and her merry band of volunteers en route

Clowning Around for LAM Action

Joan Mensor has once again been raising more funds for LAM Action as well as awareness of the condition around her local community in Burton Latimer. On April 1st, Joan and her band of hardy supporters completed a sponsored walk, and also raised funds from a raffle in the local library.

Some regular readers of LAMPost may recall an article away back [Editor: Summer 2021 edition], on how I, as an artist was making 100 handmade fundraising cards in respect of Uncle Tom's challenge. Well, in the middle of winter, looking forward to Spring, and again with Uncle Tom in mind, I thought about doing a fundraising walk. I had by then received ambulatory oxygen which was giving me the freedom to get out and about more, and I realised that in one day I could raise far more money than the time it took making cards.

I wanted to do it in early Spring to help people through the winter, and as I had done a bit of clowning in my previous history, I chose the date of April 1st, April Fools' Day to hold it. All the walkers would be invited to dress up as clowns or anything silly, and that would certainly raise awareness!

All the planning was going well, thanks to the wonderful help from Burton Latimer Community Library. Excitement was growing. The week before we had beautiful Spring weather. April 1st duly arrived, and we were plunged back

into winter! The colourful balloon was deflated, but not completely. Despite the cold, and despite committed walkers going down with COVID, a few valiant volunteers turned up, including my husband and members of my family, and five dogs, and we set off round the village. Dressing up as clowns was challenging wearing winter clothes, but I just smothered myself and my scooter (I was allowed to use it at walking pace) in brightly coloured spots, jammed on a silly hat and wey-hey we were off!

There was a great feeling of camaraderie, and we visited all the shops which had kindly donated items for the raffle to swell the funds. Round the village and back again to a welcome hot drink and cake. Looking round at their lovely cheerful faces I felt what a great thing they had done in supporting me in this way. It might appear on the surface to be a small effort, but I am a great believer, in these difficult times, that even the smallest things we do for others is great. I'd like to close by offering a poem that I wrote recently on this theme:

*Oh, the sacredness of small things,
those myriad sweet saviours of the divine.
Ethereal birdsong
heard as the lullaby of angels.
The sudden flash of colour on a dragonfly wing
seen in the quick exchange of smiles
between passing strangers.
Those precious talismans of hope and wonder
bringing minute miracles each day
enabling, empowering
the small steps of dreamers
to become the true giant steps of mankind.*

Once again, thanks to all involved, including the encouragement of LAM Action. Bless all you Lammies out there. Just keep fighting the good fight!

Love Joan x

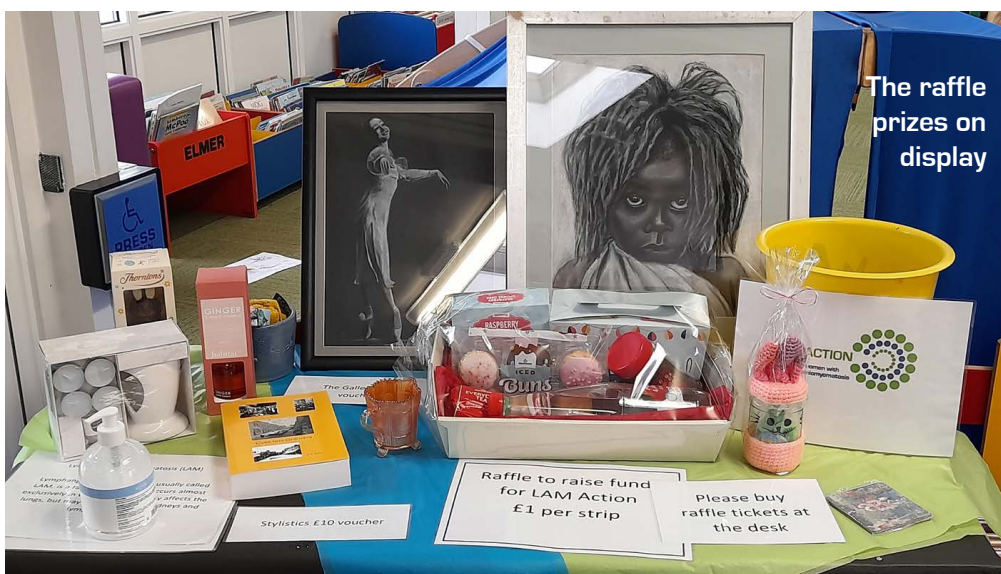
Editor: A big thanks from us all to Joan and all her crew who took part in the walk, also to all the local businesses who helped and donated prizes.



Making the raffle draw in the library



Out and about in Burton Latimer



The raffle prizes on display



Outside Corby Kilns, one of the supporting local businesses



Life as a Lammie

New LAM Action Trustee Harriet Saunders is certainly not one to let her LAM diagnosis stop her from enjoying life to the full, and she is not afraid of getting her hands (and just about everything else) dirty to help raise funds for us.

When I was diagnosed with LAM in April 2019, initially I was in shock and truly didn't believe a fit and active 24-year-old could be hiding this scary disease, which could appear at any time. To be told at 24 that you may live a shorter life and your disease is incurable is a very scary thing to face. I'm not even too sure I have got my head around it now!

However, I have not let this disease take over my life, and I strive every day to be the best I can be. I know the last couple of years have been awful for everybody and being thrown into a lockdown and being told that you are vulnerable and need to shield for the foreseeable has been frightening. But now, we are hopefully starting to see a little normality return.

Last year, I took part in the Wolf Run 10km mud run, which was challenging and very muddy but overall super fun! This year, I was determined to take on my next challenge. Although being triple vaccinated, I still managed to get COVID in January 2022, however I was extremely fortunate,

and I was basically asymptomatic, and it did not impact my health. I was given the go ahead to go snowboarding, something which I hadn't done since before my diagnosis.

Honestly, I was anxious about going. I hadn't been exposed to altitude since my pleurectomy and bullectomy and thought of being in a cable car really did scare me. We decided to drive to Switzerland from the UK instead of flying as we wanted to experience more of France along the way (as well as brining back some nice wines!) and it was the perfect journey. I thought I would be tired after a day of travelling however on the first day we arrived at the slopes, I was feeling great! I did settle into the altitude slowly, and went from 800m altitude to 1500m, waiting for two hours before going up into 2500m altitude.

The first day was perfect and I really surprised myself with how well I felt. The second day, we went straight up to 2500m altitude, and this was a little trickier and I definitely struggled a little with fatigue on that second day. I just rested in the bar and thanks to the help of an aperol spritz, I felt much better in the afternoon. We then ventured to 3000m altitude, and it was truly so much fun!

The whole experience was so much better than I could have ever dreamed. Although I did have a little fatigue at times, it didn't in any way ruin the trip. I would highly recommend anyone with LAM who is considering going skiing or snowboarding to go for it. We put in all the precautions, getting health and travel insurance, and getting all of the emergency numbers saved to my phone. More importantly, I listened to my body when I felt tired and took rest whenever I needed it. Eat lots of energy providing foods, and just enjoy the whole experience.

Back when I was diagnosed, I really thought this was never going to be achievable again, but I was wrong. I don't regret a single thing and I cannot wait to go again!

Harriet Saunders



Mud, mud, glorious mud! Harriet and her partner Adam



Hitting the slopes...



Ain't No Mountain High Enough!

The next edition of LAMPost will be out in Summer 2022 with a deadline for submissions of **July 30** - thank you!

LAMPost Editor John Wood

Sub-editor Francesca Cook

lampost@office.lamaction.org

LAM Action Chair Leanne Lillywhite-Sutton

LAM Action Co-ordinator Jill Pateman

jill.pateman@office.lamaction.org

Donations: Sarah Sharples

finance@office.lamaction.org

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

Jill Pateman, LAM Action Coordinator

LAM Action, PO Box 10933, Newark, NG24 9QG

For online donations, visit

www.justgiving.com/lamaction

Medical Team

Professor Simon Johnson

Professor of Respiratory Medicine

Director of the National Centre for Lymphangioleiomyomatosis

University of Nottingham, D Floor, South Block, Queens Medical Centre

Nottingham NG7 2UH

Professor Anne Tattersfield

anne.tattersfield@nottingham.ac.uk

London Marathon / Ride London

David Mercer

Surrey House, Peaslake

Guildford, Surrey

GU5 9RL

david.mercer@office.lamaction.org

