

APRIL 2023

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Ale and Hearty for
LAM Action

From the Editor's Desk



After what seems like endless months of winter, spring is finally here! We hope that you have been able to enjoy the lighter evenings and that you had a nice peaceful Easter break with lots of chocolate.

Hopefully everyone will now already be aware that the 2023 LAM Action Annual Meeting will take place in a purely virtual format on **Saturday June 10th**. We had been hoping to instigate a return to face to face meetings for those who felt comfortable to do so, however when we surveyed our membership, the results indicated that there would not be enough attendees to make holding an in-person event viable. You can however still look forward to another interesting and informative meeting in an online format. We are still fine tuning the details so please watch this space for more details on the meeting content, as well as instructions for joining the event.

Everyone at LAM Action was deeply saddened to hear of the passing of Susan Greener in February. Susan would have been familiar to anyone who had attended a LAM Action Annual Meeting in the years before COVID, as she was always a regular, and readers of LAMPPost may recall a very helpful article she wrote for us a few years ago on panic attacks. Gill Hollis has penned a lovely tribute to Susan that you can read on page 6.



We have been lucky to have been the beneficiary of some great fundraisers over the last few months and you can read about the event featured on the cover later on in this edition. We were pleased to be able to provide posters describing what the charity does, which not only helped

with the amount of money raised, but also helped raise the profile of LAM Action and the condition itself. If you are planning your own fundraiser and would like promotional materials such as posters and flyers to help publicise your event please get in touch with Jill Pateman, and we will gladly provide them.

On the subject of fundraising, a massive thanks from all of us to **Dominic Hall and his band**, who raised a whopping £354 for us at their Christmas Concert back in December. We are sure there have been other fundraisers that have taken place on our behalf that we have been unaware of, but rest assured we value each and every penny you raise for us and send a big thank you to all of you out there who keep us going with your amazing fundraising, even if we are unable to recognise you officially!

As you will read, we have two major upcoming events, the London Marathon and Ride London. It's great to see that LAM Action will be well represented in both events and we know all our runners and riders will greatly appreciate any support you can give them along the way, and also by way of donations.

A big thank you to everyone who has contributed to this edition of LAMPPost, and great to see another new contributor once again. Without your articles there would be no newsletter so please keep them coming!

LAMPPost will return in the summer, with a publication deadline of **August 21st**, please email any articles or other contributions to: lampost@office.lamaction.org.

Until then please enjoy the better weather, keep safe and well, and very best wishes from the LAMPPost Team.

Cover Photo: Raising a glass for LAM Action at the 13th Elysian Beer Festival. On the left is the Head Brewer at Cambridge Moonshine Brewery with his assistant far right and in the middle is one of the brewers of the Three Blind Mice Brewery.



Exciting LAM Centre News

Recent visitors to the National Centre for LAM in Nottingham might have noticed a few new faces. Professor Simon Johnson has expanded his team, which means more consultants and nurses to care for people with LAM.

Professor Dominick Shaw, Dr Sy Giin Chong and Dr Gauri Saini have joined Professor Johnson as consultants at the centre. Professor Shaw is a Professor of Respiratory Medicine specialising in high quality campus-to-clinic research and is head of service for the respiratory speciality in Nottingham University Hospitals Trust. His experience includes considerable work involving airway disease, biomarkers and digital health.

Dr Chong is a specialist in interstitial lung disease. She trained in Canada and Ireland and is a former Fellow at the Firestone Institute for Respiratory Health in Canada. Dr Saini trained as an NIHR Academic Research Fellow in Respiratory Medicine at the University of Nottingham School of Medicine. She also is an interstitial lung disease specialist and has been involved in numerous clinical trials and research.

In addition, Shannon Bradley-Hewes has joined Hollie Gorensweigh as part of the nursing team. Shannon has worked with respiratory conditions and in palliative care and is quickly getting up to speed about LAM.



Prof. Dominick Shaw



Dr Sy Giin Chong



Dr Gauri Saini

The new team members join Wendy Somerfield, who continues as centre co-ordinator, and Professor Johnson, who continues in his role as a consultant and the clinical lead for LAM.

The centre saw 268 people with LAM last year, including over 177 in face-to-face visits. Having spent the past 11 years as the only consultant at the centre, Professor Johnson is delighted to welcome the new members to the team and thinks that this puts the centre's future ability to care for LAM patients on a solid footing.

Kelly Vance

If you have visited the National Centre for LAM then Professor Simon Johnson and the rest of the team in Nottingham would be delighted to hear your feedback. What worked well for you? What do you think we could be doing better? All feedback will be treated in the strictest confidence, so please take a few minutes to email them at nuhnt.lamcentre@nhs.net with your thoughts on the service - this will help improve the experience even more for our future visitors. Thank You!



Remembering Susan Greener

Susan Greener, who passed away on 13 February 2023, was a friend to many in our LAM community. She was one of the most stoic too. After waiting on the transplant list for six long years, we were delighted when Susan finally got her call for new lungs in May last year. Initially she recovered well but, cruelly, within months she had developed cancer which ultimately resisted treatment.

Susan was a regular at LAM Action's annual meetings in Nottingham. In this photograph, taken at Nottingham Station after our 2011 meeting, Susan is on the far right. A group of us were catching trains and it turned out that Susan and I were booked on the same train north. We talked all the way to Newcastle and the time just flew! In that photo, Susan is just as I remember her – ebullient, warm and smiling. Her cheerfulness was infectious.

In the following years, she was a huge support to others in the LAM community. She helped us with Spanish translation on several occasions, and latterly helped moderate our online Facebook support group. That's not an easy task at times, but Susan was always sensitive and concerned for others, even when she was facing considerable problems herself.

Susan's daughter Emma gave the eulogy at her funeral mass. It sounded as if Susan faced the other challenges in her life with the same determination and positivity that she did with her LAM. She had started studying law at university but dropped out to marry and move to Spain. While there, she embarked on an Open University degree in Humanities. She was still living in Spain, but by then a single mum to Emma and her brother Alex, when she was diagnosed with LAM and, in these pre-rapamycin days, her health began to deteriorate. With the support of her parents, the little family moved back to Newcastle and Susan went to university there, graduating with a degree in Music. Her dissertation was on tango! She followed this with a post-graduate teaching diploma that paved the way for her to teach in schools around the north-east. Later, she completed the Open University Humanities degree that she'd started in Spain, with a particular focus on Spanish studies.

Music was a big part of Susan's life; as well as being an accomplished pianist, she also played violin in an orchestra and - remarkably, given her declining lung function - she sang in a choir. She was a keen crafter too, enjoying knitting and crocheting. After her transplant, she was looking forward to resuming all these activities and associated friendships.

We know that transplantation brings risks but, of all people, Susan deserved a happy ending. She possessed grit, resilience and optimism in spades, and was a caring, cheerful friend to many in the LAM and transplant communities. We will miss Susan greatly, and our thoughts are with Susan's beloved family, especially her parents, Derek and Marina, her children Emma and Alex and her three young grandchildren.

We are also grateful to the family for carrying out Susan's wish that donations in her memory be made to LAM Action.

Gill Hollis



It's a Cat's Life

Tina Dickinson was able to get through lockdown by fostering some furry friends who were in need of help, and found it a very worthwhile experience.

When lockdown arrived, I suddenly felt alone and being in the shielding group even my food was left outside. My immediate thought was “so what can I do now that’s meaningful”. I spent time on Facebook and Google and found Cat’s Guidance Rescue. When I was younger, I had goldfish, gerbils, budgies, tortoises, cats and dogs but suddenly found myself home alone.

Cat’s Guidance Rescue are a local charity that bring in lost, stray, sick and unwanted cats. The thing that drew me to them was that they rescued, rehabilitated, and rehomed the ones that other pet charities would put to sleep because the cost of future care was too great.

I explained my situation and explained what LAM was and how it affected me. One of the founders, Sam, came to my apartment and did my home check from the garden. Shortly after, my first foster cat arrived. I was totally unprepared! Despite having kitted my home out with toys, beds, playthings, rugs, bowls etc I had totally forgotten how to give medication etc and thought oh heck I’ve made a mistake here. My foster cat was soon

taken back to someone who could do the job much better than me, and I was so deflated it was unreal.

Anyway, they didn't give up on me and foster cat number 2 arrived, without medication, and I soon got used to caring for cats again. The overwhelming emotion you get once they are adopted, and you know your care has led to them being able to have a loving and stable home is fantastic.

Since then, I've cared for another 6 cats and am totally equipped for the giving of medication! Yes, I fall in love with all of them, but I know if I let them go then my home is free to help the next one. They're all different and they all fill a little piece of your heart.

When my little old lady Audrey arrived, we found she only had a few months left to live: With love and the correct care she was with me for 18 months and incredibly happy. That was a beautiful 18 months she would never have had with other charities.

Charities are often full and there is a waiting list but if you can get a stray cat to a vet to check for a chip and keep them safe for a short while they will get back to you. Please contact your local charity rather than keep feeding the cat so they can help it to start a better and loving life. If you are in the Northwest please contact Cat's Guidance Rescue: the small cat charity that cares for those that other rescuers won't.

www.catsguidancerescue.com

Tina Dickinson





London Marathon Preview

Early in the morning of Sunday 23rd April about 50,000 people will gather at Greenwich Park to begin an event that they will remember for the rest of their lives – the London Marathon. Amongst that number are 8 runners who are taking part to raise money for LAM Action. The funds that they bring in are vital for LAM Action to continue its ground-breaking research into the condition. Here are their stories and we hope that members of the LAM community who live near London can support them along the route and those who are further afield may be able to make a donation.

Chrissie Mills is a Clinical Project Manager at Papworth Hospital. She describes herself as “a devoted wife and mother of three amazing children.” Chrissie has completed a few 10km events and a half marathon 5 years ago and when asked why she wanted to run the London Marathon she wrote: “One of my dearest friends and godmother to my children has been diagnosed with LAM. If supporting this charity can offer a glimmer of hope of improved treatments, I am fully supportive and back it 100%. Working as a research project manager in the NHS I understand the importance

of investigation for treatment progression and I also have experience regarding how hard it can be to secure funds for pioneering research to help those diagnosed. Especially with the disease being so rare funding streams are limited. I am hoping to raise some funds to support research in this area. If doing something foolish like running a marathon can help achieve this, I will do my very best to drag my butt around the 26 miles of London for every penny.” In addition to running for LAM Action, Chrissie also arranged a recent raffle which raised an amazing £529 as well as a wine tasting event, a brilliant effort all round - thank you Chrissie! If you feel moved to help Chrissie’s fundraising, please go to:

<https://2023tcslondonmarathon.enthuse.com/pf/christine-mills>

Jenny Hastings is running with Chrissie Mills. She has wanted to run the London Marathon for a long time but never been successful, now LAM Action can make it possible. 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://2023tcslondonmarathon.enthuse.com/pf/jenny-hastings>



Chrissie Mills



Jenny Hastings

Mike Astley, a property accountant who lives in Knebworth, is running for LAM Action because of his sister-in-law, Caroline. She was first diagnosed with LAM when she was pregnant 12 years ago. It's Mike's 56th birthday five days before the Marathon – so the celebratory drinks will have to remain chilled until after it is done. Mike said, "There are so many charities that all want help but it's so important to help the smaller, less well-known ones and I'm delighted to be doing my little bit to help." To support Mike's fundraising effort please visit:

<https://2023tcslondonmarathon.enthuse.com/pf/mike-astley>

Andy Judge is a Criminal Barrister who works and lives in London. He took up running 3 years ago and he ran his first London Marathon in October for LAM Action. He enjoyed the experience so much that he volunteered to run again and welcomes any support for what he describes as "an amazing charity". To help Andy reach his fundraising target, please go to: <https://2023tcslondonmarathon.enthuse.com/pf/andrew-judge>



Mike Astley



Andy Judge

Rachel Stinton lives in Leamington Spa and is a friend of LAM patient, Helen Sabin. Rachel said, "I was given the Charity place in April 2020, after completing all the training and raising lots of money for LAM Action, COVID struck and the

marathon was postponed. In October 2020, COVID was still around, the marathon was cancelled and we ran The London Marathon virtually, stomping the streets of Leamington Spa. Unfortunately, injury caused me to pull out the Marathon last year, so here we are again third time lucky.” To support Rachel’s effort to at last complete the London Marathon please donate here:

<https://2023tcslondonmarathon.enthuse.com/pf/rachel-stinton>

Nick Culley will be known to many as the co-host of our Virtual Annual meetings. Nick lives in London and enjoys getting away to remote parts of the world, acting as a group leader for teams of young explorers. Nick has been involved with LAM Action for many years as the technical wizard behind the live streaming of our meetings and filming videos for the website. Now Nick is supporting the charity yet again, so if you want to help him fundraise here’s the link: <https://2023tcslondonmarathon.enthuse.com/pf/nick-culley>



Rachel Stinton



Nick Culley

Rick Nagle is an IT Project Manager who lives in the Netherlands, with his wife and young daughter. He has run 20 half-marathons, 3 Rotterdam Marathons and 3 New York City Marathons but this is his first time in London. Rick heard about LAM Action through Nick Culley so now both of

them are taking on the 26-mile challenge. To support Rick, go to: <https://2023tcslondonmarathon.enthuse.com/pf/rick-nagle>

Paul Thomas from near Kidderminster is a friend of LAM Action's chair, Leanne Lillywhite-Sutton. He is training to be a plumber after a massive career change. He first ran the London Marathon in 2018 but hasn't run much since then and has enjoyed getting back into training again. Paul says it will be an honour to wear a LAM Action vest around London and he wants to raise as much as he can for the charity. To help Paul with that aim please go to:

<https://2023tcslondonmarathon.enthuse.com/pf/paul-thomas>



Rick Nagle



Paul Thomas

We wish all eight runners the best of luck on 23rd April and please do come out to cheer them on if you can – it's a great family event.

David Mercer



Under the Microscope

People who have contacted the National Centre for LAM in Nottingham likely will have encountered Wendy Somerfield. Wendy is the centre Co-ordinator who schedules patient visits, fields phone calls and queries and generally keeps things on track. In our occasional column about the medical professionals who help people with LAM, we get to learn more about Wendy.

Could you please tell us a bit about yourself?

I have lived in Nottingham all my life and grew up in Keyworth. I was never very academic, being more interested in sport, and left school at the age of 16 and started my first job in a local architect's office. I have had various office jobs which have included various admin roles in a local architect's office, timber company, Nottingham City Hospital, insurance company, shop fitters, Boots the Chemists and Makro Cash and Carry. I re-joined Nottingham University Hospitals in 2012 (previously having worked at the City Hospital in the Outpatient Clinic prep team) in the Pharmacy Department as an Administrative Team Leader and eventually joined the LAM Centre.

I have been married to Nigel since 1985 and have two children, Lindsey who is 33 and Luke who is 21. I also have a grandson, Dylan, who is 4.

I was an enthusiastic hockey player from school days. I was selected for the County team and played in the first team, and I ended my playing career for Boots HC in my mid-forties. I also attended the gym regularly.

Had you heard of LAM before you joined the LAM Centre? How long have you been with the Centre and how did you end up working there?

The first time I heard of LAM was when I saw the job role at the LAM Centre advertised. I joined in 2018 when I was ready for a change from Pharmacy, as I was keen to contribute to patient care.

What is your favourite part of the job?

I really enjoy helping patients with their queries and making sure their visit is as smooth as possible. This is especially rewarding when new patients are anxious and nervous about their first visit. I feel as though I contribute to their visit being as smooth as possible in a worrying time for them.

I feel very privileged to be able to work for Prof Johnson and his team.

In the past year or so, the care team has grown from one consultant (Prof Johnson) and one nurse to four consultants and two nurses. How do you think all of these changes will affect you and your job?

I think the changes are very positive and very much needed for continuity of care for our patients and also for succession planning. We have a growing caseload that is getting increasingly difficult to keep on top of, so this can only be good news for our patients.

This will create a bigger workload for me but there are talks of getting some admin support too so that my job, which is already more than full time, doesn't get too

overstretched and this will help succession plan for me too which is very positive.

I feel very happy about these changes and hope that they will reduce our waiting times significantly.

How do you unwind from work or spend your free time?

I love walking and have an Airedale terrier dog who helps me to get motivated to have lots of long walks.

I enjoy travelling to the Canaries for some winter sun most years.

Lots of family time too. We have ageing parents that need lots of support, but we enjoy spending time with them along with the children and grandson.

Do you have any advice for people who have never visited the LAM Centre and are debating whether to seek a referral to Nottingham?

I would strongly encourage them to get referred and make the journey if they are able to.

I have seen a lot of anxious “new” patients who really aren’t sure what to expect but when they have had their consultation you can really see that a lot of their worries have been lifted after their first consultation.

I think we endeavour to give a “first class” service from first appointment with all the tests needed on the same day and active follow-up from then if needed.

Wendy was interviewed by Kelly Vance

Glasgow Kiltwalk 2023

On Sunday 30th April Mary-Clare Blacklaw is taking part in the Glasgow Kiltwalk to raise money for LAM Action. Here's Mary-Clare's explanation of why she is doing it:

I am aware of LAM Action as one of my best friends lives with the condition. Previous to her diagnosis, none of us were aware of this rare disease.

This is my first sponsored event – and for those of you that know me - no you are not dreaming - I am indeed walking 14.3 miles. Well, I say I am walking it, I may be crawling it by the end!!! It is just as well I am doing it for a very important charity that is very close to my heart.

Currently, around 400 women in the UK have a diagnosis of LAM. One of those 400, is one of my 'bestest' friends. She lives with it every day, taking each day as it comes and getting on with it. Some days are better than others and certainly the time of year plays a part too. None of which she allows to stop her living her best life.

I don't normally ask for any sponsorship and appreciate that times are difficult for everyone, however if you could spare me any amount towards a donation it really would be very much appreciated.

Thank you in advance for taking the time to read this and any donation you are able to make. Wish me luck - I will need it :-)

To support Mary-Clare's effort please go to:

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





Georgia's Story

My name is Georgia and I was diagnosed with LAM in January 2022.

At the start of January, I had terrible chest pain/symptoms of a chest infection and was given antibiotics by my GP, after no improvement I was told to go straight to A&E. I was admitted to hospital after an X-ray and blood tests and the following morning I was told I had LAM by a respiratory doctor. After a few days in hospital with my pain only increasing, I had my chest drained of nearly 800ml of fluid from my right lung as I had a chylous effusion. I spent a week in hospital and was then discharged home with my new diagnosis.

After about three weeks at home my pain returned and I had to go back to hospital to have a further 1500ml of chyle removed. I was then prescribed 2mg a day of Rapamune which has prevented any further chyle build ups and prevents the disease from progressing too much.

The first few months after my diagnosis were extremely tough, I felt like I would never get back to my life before

LAM. It felt like it took ages but when I look back I realise how far I have come. Considering what my body has been through I am doing really well.

I can enjoy walking my dogs every day, I can go out and socialise and I have returned to work and my studies as normal. I have been very lucky because my family, my boyfriend and my best friends have been so supportive. My career is very important to me, I am currently a paralegal and hope to qualify as a solicitor. Although I have had a setback, I can still work towards this goal. I have also been able to travel as usual and have visited new cities which I love doing. Life is not “normal” but it is very good.

Georgia

Follow Georgia on Instagram: **georgelam2022**

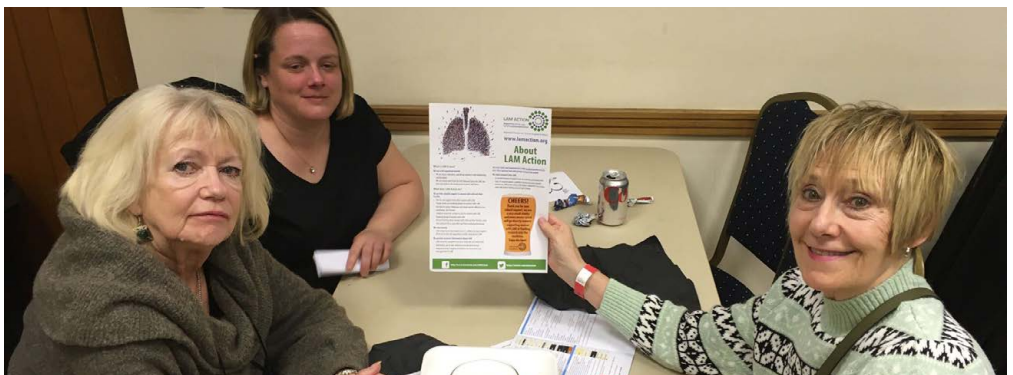




Raising a Glass for LAM Action

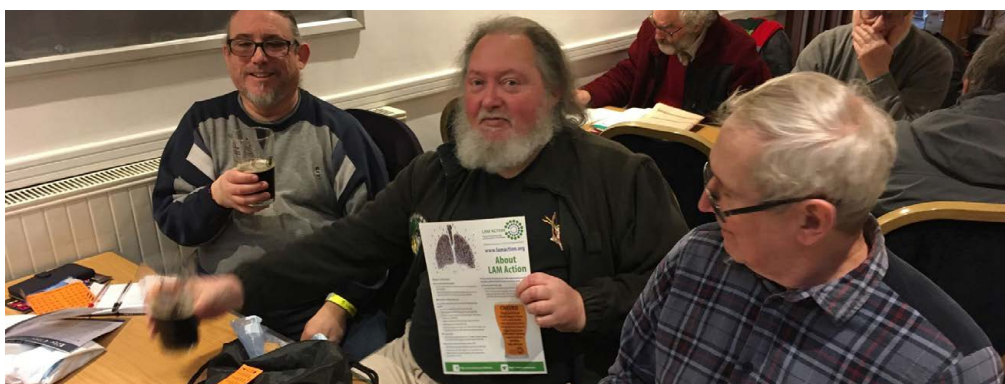
The 13th Elysian Winter Beer Festival was held on 3rd-4th February at the Maltings in Ely, and LAM Action were fortunate enough to be named as the festival's charity of choice. Big thanks from all of us to Ely & District CAMRA (Campaign for Real Ale) and to the Larwood family for choosing us and for your fantastic fundraising on our behalf.

Adrian Larwood said, "The reason why I put LAM Action forward to the Ely CAMRA branch is that my wife Karen has this condition, so it was an obvious choice for me. At the follow-up meeting, the charity was chosen above all the others put forward as it was felt that it was not as well-known as other charities, so it would be a good chance to make more people aware of it. The branch does tend to pick local or lesser-known charities to support. On a personal note, I was overwhelmed that it was chosen by a considerable show of hands when it came to the vote.



We are currently unsure as to the exact amount raised, as we are waiting for the St Albans head office to check and verify the funds raised for the charity. But I was led to believe by the festival finance team that it was the most successful fund raising the branch has ever had.

On a final note, some of the team who worked at the festival are Cambridge branch members who work at their beer festival, which is one of the biggest in the country, and they are going to put LAM Action forward as a possible charity for next May's festival!"



Ride LONDON ESSEX 100

Ride London 2023

On 28th May there is another major event in LAM Action's fundraising calendar – Ride London. This 100 mile cycle from the Embankment through the leafy lanes of Essex before finishing on Tower Bridge attracts thousands of entries and this year 8 of them are raising funds for LAM Action.

At the top of the list of avid cyclists is the director of the LAM Centre in Nottingham - **Professor Simon Johnson**. Simon is joined by his daughter, **Naomi Johnson**, her boyfriend, **Oscar Mahoney** and friend, **Alex Slater**, who all live in London.

<https://2023ridelondon.enthuse.com/pf/simon-johnson>

<https://2023ridelondon.enthuse.com/pf/naomi-johnson>

<https://2023ridelondon.enthuse.com/pf/alex-slater>

<https://2023ridelondon.enthuse.com/pf/oscar-mahony>



Professor Simon Johnson and his daughter Naomi



Oscar Mahoney

Also raising funds for LAM Action are **Lisa Cooper** and her fiancé, **Kevin Jones** from Bracknell, Berkshire. Lisa was recently diagnosed with LAM and has had operations on both lungs to try to stop them collapsing, but she is still determined to take part in Ride London. For Lisa and Kevin 100 miles is not enough, they are taking on another challenge in July, riding 330 miles from London to Paris in 4 days.

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



Lisa Cooper



Kevin Jones

Andrew Barham is a property developer from Twickenham, London. He was first due to ride for LAM Action in 2020, when the pandemic led to the event's cancellation. He tried again in 2022, but a bad crash during training left him unable to take part. So now let's hope it is 'third time lucky' and he completes the course safely.

<https://justgiving.com/fundraising/andrewbarham2>

Simon Fairbrother is a friend of LAM Action trustee, Sally Merritt-Collins. Simon is an engineer who lives in Bewdley, Worcestershire. He took part in last year's Ride London and enjoyed it so much that he volunteered to do it again this year.

<https://2023ridelondon.enthuse.com/pf/simon-fairbrother>



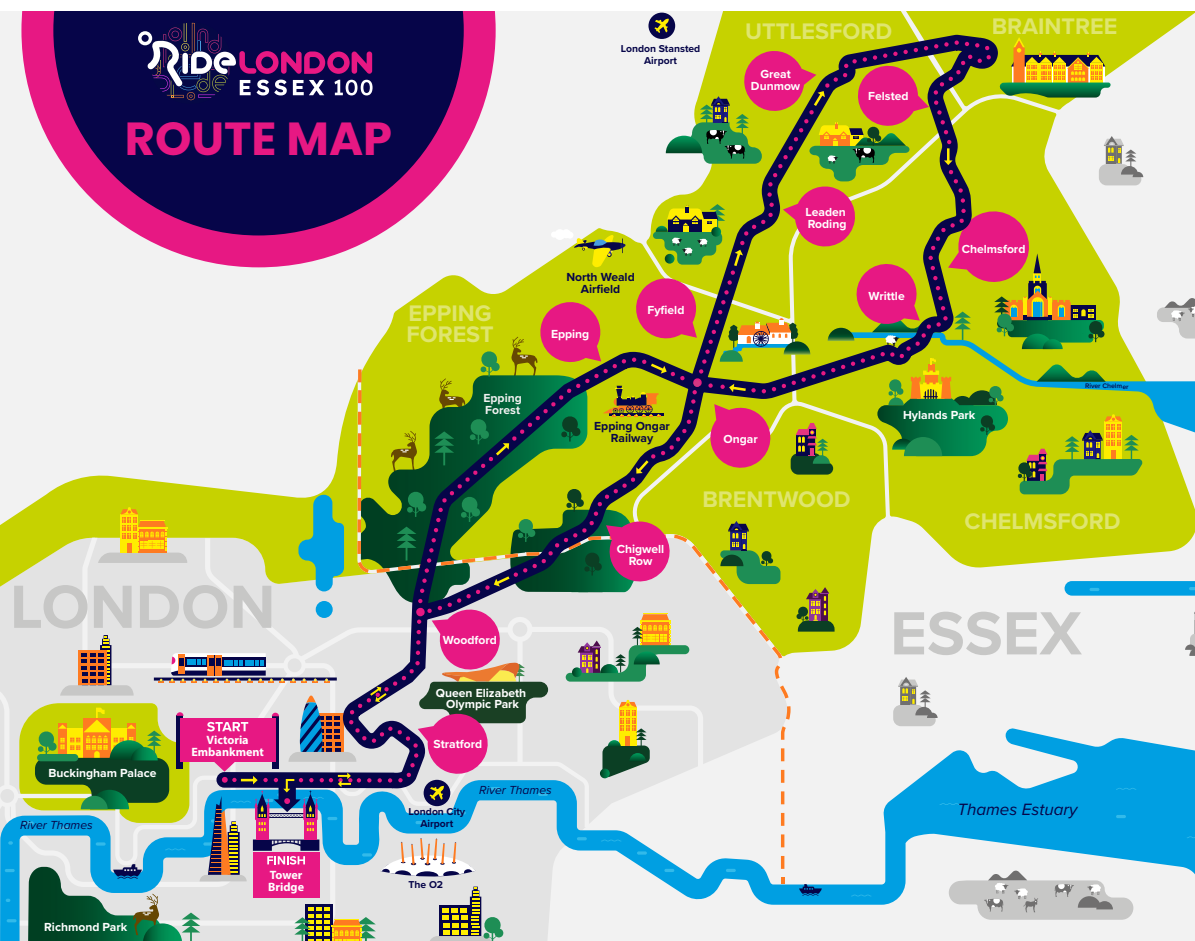
Andrew Barham



Simon Fairbrother

If you'd like to show your support for any of our riders by making a donation their fundraising pages are below and if you live anywhere near the route they would really appreciate seeing you along the way. Please e-mail **david.mercer@office.lamaction.org** if you are going to be out on the road and I will make sure the riders look out for you.

David Mercer



The next edition of LAMPost will be out in summer 2023 with a deadline for submissions of **August 21st** - 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

