

SEPTEMBER 2022

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Celebrating 25 Years



From the Editor's Desk



Welcome to the summer 2022 edition of LAMPPost, and we hope you are all well and have been enjoying some nice warm sunshine, while managing to also keep cool during the unbearably hot recent heatwaves.

Once again we have a very full edition for you, though I did have my usual panic when the publication date was edging nearer and yet our inbox remained barer than Old Mother Hubbard's cupboard, but it all came together in the end. Big thanks to everyone who has contributed to this edition, and we have some very interesting features for you to enjoy. Keeping an eye on the charity's two Facebook pages, it would seem there are quite a lot of recent new faces in the UK LAM community, and we really would like to hear from you, even if it's just a few paragraphs to introduce yourself – everybody has a story to tell, and it would be great to have some fresh contributors to the next edition.

As we go to print, it is hard to believe it is almost 3 months since the LAM Action Annual Meeting, which took place on Saturday June 11. A hugely enjoyable event, expertly presented with consummate professionalism once again by David Mercer and Nick Culley (just how many cakes DID you eat Nick?!), and a lot of the feedback we received after the meeting echoed our view that it was perhaps the best meeting we have ever had, which was a fantastic way to help celebrate the 25th anniversary of LAM Action.

You can read more about the early years and development of the charity further on, and we are indebted to Anne Tattersfield for providing such an informative and fascinating piece which charts the growth from the very first meeting of LAM patients in 1997 through the next six years up until 2003, a truly remarkable story of how much

can be achieved through hard work and perseverance by a few driven individuals.

Talking of Annual Meetings please make a note in your diaries already for next year as we are planning to hold the 2023 meeting on **Saturday June 10th** – this is being planned as a ‘hybrid’ meeting which will allow those who wish to return to attending face to face meetings to do so, while also allowing those who are less comfortable with that idea to watch it online. The meeting venue will be the Mercure Nottingham Sherwood Hotel (TBC), and we are very much looking forward to reviving the whole social aspect of the meetings and seeing lots of old friends again. Further details will follow in due course, but for now please save the date and we hope to see as many of you as possible, either in-person or online.

Fundraising is slowly starting to recover from the two pandemic years and you can read about some of the events that have happened and will be taking place further on. A big ‘thank you’ to everybody who has raised funds for us and a quick shout out here to Lucy Edmunds’ sister Sandra Bull who collected donations at her 50th birthday party raising £350. Please do let us know if you are fundraising for us as we would love to say thank you to each and every one of you!

LAMPost will return just before Christmas, with a publication deadline of **November 30th**, please email any articles or other contributions to: lampost@office.lamaction.org. Until then please stay safe and well, and very best wishes.

John and Francesca



Nick Wadsworth

Everyone at LAM Action was deeply saddened to hear of the recent passing of Nick Wadsworth. Anybody who has been to one of the Annual Meetings in recent years would have had the opportunity to meet Nick, as he was always in attendance alongside Joy.

As you will read further on, Joy and Nick were very much involved in the early years of the LAM Trust/LAM Action, and as LAMPost editor I am humbly following in their footsteps as they were among the very first editors of the patient newsletter and even came up with the perfect name LAMPost.

It was only through the efforts of dedicated people like Nick that we were able to develop the charity from its first hesitant steps to the successful and patient-focused organisation that we recognise today.

Thank you Nick for all you did for us, and everyone at LAM Action sends their heartfelt condolences to Joy.

Introducing Tess Hill

Hot on the heels of Harriet Saunders, we are delighted to announce Tess Hill as a Trustee and Committee Member of LAM Action! Welcome aboard Tess and we look forward to seeing you at our next meeting in September.



Hi Everybody,

My name is Tess Hill and I was diagnosed with LAM in November 2021 after having my baby boy who is now nearly 10 months old. He is very healthy and has brought a lot of joy to the family, he is our ray of sunshine. Whilst being pregnant, I had an experience of presenting with bilateral pneumothoraces, this happened twice during my pregnancy. I had a total of 5 pneumothoraces and 8 chest drains. It was a very scary and tough time. I was very unwell and in a lot of pain. I managed to get to 36 weeks and had a c-section which went well.

I had surgery at 24 weeks pregnant which was very scary. This was to try to prevent anymore pneumothoraces during the rest of my pregnancy. There was not much experience of carrying out this procedure on a pregnant woman, so as you can imagine it was a very worrying time for myself and partner. It was the health of my own to worry about as well as my babies. After the pregnancy I had a pleurodesis on both lungs. I had an amazing consultant, thoracic surgeon Juliet King at Guys Hospital in London who looked after me and made me feel very safe and she made the experience 100 times better. I am very thankful that Guys knew what LAM was and I was diagnosed very quickly after having a biopsy on my lung and a CT scan to confirm this. I am a healthy person who doesn't smoke or drink and has a very active lifestyle, so this all came as a bit of a shock to me.

My life has changed a lot since having LAM, I appreciate my life more and never take anything for granted. I am finally in a good place where I am being very well looked after by my doctor, Dr Kokosi and her team at The Royal Brompton and Guys Hospital in London. I feel safe and my health is being well managed. I am a very positive person and I focus on the good in everything. I am pleased to join LAM Action as a committee member, and I am hopeful and positive for the future of LAM.

I am currently planning a wedding in Italy with my fiancé, and I am looking forward to the future with moving into a new family home. We live by the sea which is very calm, and I feel this is great for my mental health.

I have recently started taking Rapamycin 1mg which is going well, since starting Rapamycin I haven't had any side effects and I am hoping it stays that way. I am thankful for my little boy as I feel if I had never got pregnant, I would never have known I had LAM and it could have been a different story in 20 years' time. I am pleased I have found out about my diagnosis at a young age as it can be managed well. I am planning to do a lot of fundraising over the next couple of years to raise as much money and awareness about LAM and I am hopeful in the future we will be able to find a cure with the massive breakthroughs happening in science. I have spoken to some truly amazing LAM patients who are inspirational, and I feel lucky to have found this community which has really helped me with being newly diagnosed.

Tess Hill





Remembering Lucy Falconer

On Sunday the 19th June 2022 I had the honour of attending the Memorial for Lucy Falconer in her hometown of Aylesbury. For any of you reading this that don't know Lucy I will fill in the blanks a little...

Lucy was a LAM patient. Lucy was also so much more than just a LAM patient. She was an incredible woman from whom I learnt so much about life and how to live it. A strong and tenacious lady who fought for others while facing huge personal battles, of which LAM was only one.

Lucy was diagnosed with LAM in 1989, a time when there were no treatments available and extraordinarily little was known about the disease. Not to be deterred, calling on her intelligence, wit and wisdom, Lucy co-founded the original LAM Action – then known as The LAM Trust.

In the following Eulogy, which was read out at the memorial by close friend and fellow LAM Patient Zoe Sutherland alongside a fellow Breathe Easy Group attendee (Lucy was also hugely involved in Breathe Easy, Aylesbury), you will read a lot more about the wonderful work that Lucy went on to do for LAM Action and the startling ability that she had in sharing her wit, intelligence, and amazing strength with so many of us.

Helen Sabin

Eulogy: Lucy Falconer 1955-2020

Lucy was born on a large farm in Kentucky, the only daughter, with three brothers. The farm was very much a family farm handed down through the generations, with her uncle and cousins all living on it. Her friend from childhood was Beth.

They went to school together and when they got home, they would spend two hours a night on the phone to each other, usually discussing the local basketball team, the Kentucky Wildcats, to whom they were utterly devoted.

Lucy took a BA in English at Northwestern University, Chicago; followed by a diploma in French at Grenoble University. From there she moved on to Kent University at Canterbury for an MA in English and American Studies. It was there she met Terry, and they married in 1979.

They started their married life in America but soon returned to England where Lucy stayed for the rest of her life. Although Lucy thought about changing her citizenship in the end she preferred to stay an American. It wasn't always easy for an American to adapt to British ways, especially with driving but she managed, eventually.

Lucy had two children: Thomas, born with spina bifida and hydrocephalus, and Helen, two years younger. Thomas took a lot of caring for and his health could be precarious. So it was some years before Lucy returned to work and she then devoted herself to the caring professions.

From her youth Lucy had been interested in music. She played the flute and joined the Louisville Youth Orchestra where she became friends for life with Diane Grover. Diane and Lucy went to different universities but visited each other regularly. Lucy played the flute in the Kent University Orchestra and later in the Wantage and Abingdon orchestras. Her children put an end to her playing days.

In 1989 Lucy was diagnosed with a lung disease known as LAM. At that time it was relatively new. It was considered terminal but over the years progress in medicine has

rendered it less dangerous for many women.

Lucy was always willing to join in research and try new treatments. Having met up with other women sufferers online she co-founded and chaired the LAM Trust (later to become LAM Action) and worked with other international groups. She travelled abroad to France, Sweden and America attending conferences and she also would visit the National Institute of Health in Washington for check-ups and learning more about recent research.

Anne Tattersfield arranged the first meeting for LAM patients back in 1997. She writes “Lucy was so supportive, and brought her experience of being to a LAM meeting in the US.”

Lucy chaired the first LAM patient group meeting. She also had a major input in ensuring that the LAM Trust got off to a good start. Many patients were anxious before their first meeting, but Lucy’s big smile was so welcoming, and her warm manner ensured that everyone enjoyed the day and made new friends, leading to longstanding friendships.

Lucy’s thoughtful opinions and wisdom helped to ensure that the LAM Trust was founded on a sound basis which has enabled it to grow over the years. Lucy was an active trustee and helped countless patients with her sound advice and sympathetic approach. Despite her increasing physical problems, Lucy was always concerned about others, and always took an interest in other people and their families.

We will all miss Lucy very much, but we are grateful that we knew such a wonderful lady.

Gill Hollis, wrote of Lucy: “She was fantastic. She had both a fierce intellect and deep empathy for other people. Hers was the voice of reason and wisdom, and she always gave calm, thoughtful advice.

Personally, when I first received my LAM diagnosis, I was 17 weeks pregnant and the doctors told me I would never live to see my unborn child finish Junior School. I was

understandably distraught. Then in bounced Lucy, who had been diagnosed 14 years previously. Lucy gave me the hope that I needed. It was years later that she admitted it was all an act. She had actually sat down for ten minutes outside the ward to catch her breath. Lucy never gave in to her illness. Thank you, Lucy for being there for me and for not letting me give up.”

This positive determination is confirmed by members of Breathe Easy. Lucy helped set up the local Aylesbury Breathe Easy Group, she ran the group single-handedly for a few years and chaired the group for over 15 years. Laurel writes how Lucy gave so much time to helping others and was an inspiration to follow in her footsteps to help continue Breathe Easy with her guidance.

Ian, once a magician Lucy arranged for Thomas’ birthday party, echoes other comments in saying how cheerful and friendly she always was. Lucy loved celebrations: Easter, Birthdays, Anniversaries and especially Christmas. She always wanted a Christmas tree covered in fairy lights, right to the very end. And she loved wrapping presents.

Lucy also loved quizzes and games. She would do Sudoku and the word wheel from the newspapers. She was also addicted to Scrabble and had international games with her brother Stephen, who lives in California.

She made many friends through her daughter Helen, and she was always very loyal and made a great effort to sustain her friendships. One friend Alison says that there are simply not enough words to express how we have the utmost admiration for Lucy’s ability to remain so positive in her outlook and determination. It has been an absolute pleasure knowing her.

Lynn who used to work with Lucy tells how Lucy was into recycling a long time ago and wouldn’t even let paperclips be wasted. She was her own person and believed unequivocally in equality in the workplace. She refused the title of Manager and remained Team Leader. She rejected

a new desk and computer and stayed with her old ones. She even declined the Manager's chair. She spoke to people and treated them as equals.

Final Words

When Lucy came out of hospital on Maundy Thursday 2019 after narrowly escaping death, she wrote the following prayer:

Dear Lord,

Thank you for giving me a second chance at life after my week of great suffering.

You've kept me alive for a reason – please reveal to me what that reason is and show me the way to fulfil your plan for me.

Forgive me my many sins of envy, arrogance, doubt, pride, unfaithfulness, and many more that I have forgotten.

You shower me with blessings – a loving husband, kind and generous friends, the beauties of nature all around me, yet too often I take them for granted. Thank you Lord for your countless blessings.

Dear Jesus wrap your loving arms around Helen; comfort her and let her feel your love.

Lord Jesus, teach me how to listen. Guide my thoughts towards ways in which I may serve you better.

In Jesus' name, Amen.



Some of the attendees at Lucy's memorial service, including Lucy's husband Terry (Centre), Zoe Sutherland, Helen Sabin and John Wood



A Wheely Great Day!

A big thank you from all of us to our Fantastic Five who took part in the Ride London Essex 100 mile cycle race on Sunday May 29th to raise some much needed funds for LAM Action.

Oli W cycled 100 miles in Ride London/Essex to support his sister Kate who has LAM and there is no stopping him when it comes to fundraising. In May he also walked 42km, took part in a 12km obstacle race and ran 20km, and to round it off will run the London Marathon for us in October as well – what a superman!



Well done to **Simon Fairbrother** for completing his first Ride London. Simon is a friend of LAM Action trustee, Sally Merritt-Collins and finished in just under 6 hours. Thank you Simon for all the training, fundraising and the ride itself from all of us at LAM Action!



Jo Boardman from Devon finished Ride London/Essex 2022 in just over 7 hours. Jo took part alongside her friend **Yann Quelvennec**. Yann also lives in Devon and cycled 100 miles for LAM Action because he wanted to support a small charity - thank you both for thinking of us and very well done!



Samir Okasha also completed his first 100-mile Ride London in 4 hours 41 minutes and 34 seconds. Samir is married to Havi Carel, who has LAM. Thanks and well done Samir!



2022 Christmas Cards

As I write this, it is approaching 36 degrees outside, so it seems quite strange to be thinking of Christmas at the moment! However, there is nothing like planning ahead, and we have already ordered our Christmas Cards for this year, which come in 5 beautiful designs.



The cards won't be arriving at LAM Action HQ until October, so this is just a sneak preview, and we will be launching them along with the order form later this year so please keep your eyes peeled on our Facebook pages and your email inboxes come the autumn!





The combined LAMS
and RAMS teams

Anyone for Rounders?

Farmers Fayre, a fantastic farm shop and restaurant in Stoneleigh, Warwickshire, held their annual charity rounders match in July and this year LAM Action was the lucky recipient of their generosity. This was especially generous considering the match was overdue by two years because of a certain pandemic! Farmers Fayre stuck with us and continued to promote the match and LAM Action as their charity of choice throughout.

12 teams took part in the tournament and thanks to my local family and friends I managed to put in 2 teams namely the "LAMS" and the "RAMS".

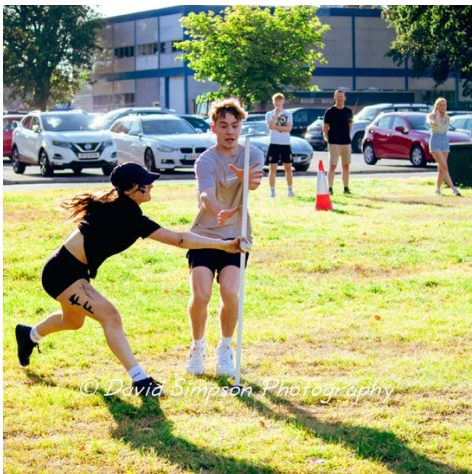
We were incredibly lucky with the weather and consequently there were a lot of spectators which really added to the atmosphere. Farmers Fayre did an incredible job with the organisation. There was street food available, an outdoor bar and music. In addition to this, Farmers Fayre also appointed 4 well organised and knowledgeable referees who most certainly did not allow cheating, despite both the LAMS and the RAMS attempts!

Prior to the tournament beginning there were a lot of teams looking profoundly serious and getting in practice while we, the LAMS and RAMS idiotically stood around swapping T-shirts (that I had printed with the LAM Action logo in a vain attempt

to look professional and scare the opposition) and chatted! It was during this ill-advised chatting, as opposed to necessary practice, that I had the pleasure of meeting for the first time Harriet Saunders and her fiancé Adam Davison. Harriet is a fellow LAM patient and a LAM Action Trustee.



Helen Sabin with Harriet Saunders



It's all about the base!

Living relatively locally Harriet and Adam travelled to Farmers Fayre to join in with the LAMS and RAMS. Both were an instant hit with the teams, it is just a shame that the teams were not instant hits with the ball!

The LAMs and RAMS fought valiantly but both teams failed at the first hurdle and neither made it to the semi-finals. Although there were a lot of full rounders by quite a few of the LAMS and RAMS there were not enough to see us through. However, we rested and took it as an opportunity to study the other teams in preparation for next year!



Time for some well-earned refreshment



Farmers Fayre Director and event organiser Nicola Reece on the mic

Despite not making it through to the semi-finals we all had a fabulous evening, and we raised a whopping **£1750.37**.

A huge thank you to everyone who helped run this event, all the players and all the sponsors.

Helen Sabin



The victorious Farmers Fayre team with their trophy - well done!

Editor: Well done to everybody who took part and a massive thanks from us all to Nicola and everyone at Farmers Fayre for their kindness and generosity in supporting LAM Action as their charity of choice! Please give them a visit, either if you are passing the area or online at:

www.farmersfayre.co.uk





Legging it Through London for LAM Action

On Sunday October 2nd the streets of London will be echoing to the sound of 50,000 pairs of feet pounding along. LAM Action will be represented once again by 6 intrepid runners, a couple of whom will be familiar faces, while others are running for us for the first time.

Alex Hanna from Burnley is a friend of the Sharples family: "I am running for LAM Action because I have friends close to me that know a lot about the charity and are affected by it, so that alone gives me a great deal of motivation, plus I admire the work that LAM Action do and I will be very proud to raise money and awareness for the charity.



Anybody that knows me knows how passionate I am about running as a sport, since the first lockdown when I went on my first run, I have fallen in love with it, and the London Marathon, that is the pinnacle of the sport, but I wouldn't stop there! After doing 3 marathons already not including this one it is fair to say I enjoy pain!"

Good luck Alex and hopefully it won't be too painful this time!
If you would like to support Alex's fundraising please visit:

<https://www.justgiving.com/fundraising/Alex-Hanna>

Andy Judge is 26 and currently practices as a Criminal Barrister in London. Alongside his work he has a keen interest in running and has done so for the last three years. He is running the London Marathon on behalf of LAM Action and welcomes any support for what is an amazing charity. Andy learned of the charity through his girlfriend Katie, who works with David Mercer, a LAM Action committee member. Good luck Andy! To help Andy reach his fundraising target, please visit:



<https://tcslondonmarathon.enthuse.com/pf/andrew-judge>

Nicki Curwood will be hoping it's a case of third time lucky, having seen two previous attempts to run the London Marathon scuppered firstly by the pandemic, and then through injury.



Nicki lives in Leamington Spa and is a friend of former committee member Helen Sabin. Nicki had originally been planning to run the 2020 marathon, alongside her friend Rachel Stinton, but then COVID came along and the race was cancelled. Undeterred by this, the pair then took part in the 'Virtual London Marathon' which took place on October 4th 2020, raising a whopping £3,773!

Fast forward to the return of the marathon in October 2021 and Nicki and Rachel were again due to take part representing LAM Action but then unfortunately injury hit them both and they had to withdraw.

So Nicki, we are keeping everything crossed for you this year that you will finally get to run through the streets of London for LAM Action and thanks for your continued and valuable support! Nicki's fundraising page is:

<https://tcslondonmarathon.enthuse.com/pf/nicki-curwood-2b2f6>

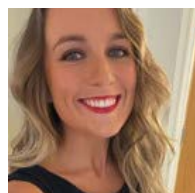
Oli W will need no introduction to the UK LAM community as he has been a stalwart of previous fundraising activities and a regular attendee of our annual meetings. Not content with resting on his laurels and taking it easy after so much effort already, Oli has pushed himself to Herculean levels this year, and the London Marathon



will be the fifth event he will have taken part in this year. Oli we hope after October 2nd you will be putting your feet up for a well-earned rest! Big thanks from all of us for your wonderful support, Kate must be very proud of you!

<https://tcs londonmarathon.enthuse.com/pf/oliver-wingrave>

Rosie Duncan from Edinburgh is a former colleague of committee member Gill Hollis. Thanks for supporting us Rosie, and looking forward to cheering you on the day!



<https://www.justgiving.com/fundraising/rosie-duncan5>

Last but not least, **Jason Springate** will be running for LAM Action having secured a place via the ballot. "Running my first marathon since knee surgery in 2018, I wanted to have extra motivation and couldn't think of a better cause than LAM Action. Living through Covid and the birth of our first child has certainly brought home the realities of LAM for me and my wife, who was diagnosed with LAM in 2010. So it felt there was no better time to be raising money and awareness for such a great organisation!"

<https://tcs londonmarathon.enthuse.com/pf/jason-springate>

A big thank you also to **Josh Brand** - Josh hails from Lexington in Massachusetts, USA and was due to run for LAM Action but sadly was unable to take up his place after all. However, Josh has very kindly donated \$250 to LAM Action and left the following message: "Good luck to all the LAM London Marathon runners. Please split this among them if you can." Thanks Josh, greatly appreciated by us all!



Patients outside the Clinical Sciences Building with Simon Johnson and Anne Tattersfield in 2003

LAM Action at 25 – a History

To mark the 25 year anniversary of LAM Action, Anne Tattersfield looks back at the very beginnings of the charity and provides a fascinating insight into the formation of the very first patient organisation, and charting the extremely rapid progress made in the first six years up until 2003.

Well, it started from small beginnings nearly 30 years ago, thanks to the dogged determination of one patient, Eva Rathbone. Given a diagnosis of LAM - then known only as Lymphangioleiomyomatosis - by my surgical colleague, Eva was understandably upset to hear that virtually nothing was known about the condition (true) and, worse still, no one was doing any research into it as far as he knew (also true). When she pestered him further he approached me to see whether we could help. Luckily one research fellow, Irfan Wahedna, had some spare time and so we wrote to all the chest physicians in the UK to find out how many patients with LAM they were aware of. We then sent a questionnaire to the 21 patients identified to obtain some fairly basic data. This led to our first publication, in the journal Thorax in 1994 entitled 'Relation of pulmonary Lymphangioleiomyomatosis to use of oral contraceptive pill and fertility in the UK; a national cohort study'. Sadly Eva died from an unrelated condition shortly after and never saw the fruits of her perseverance.

Two things then happened. A young doctor called Simon Johnson joined the department, initially to do some research into asthma. When this project faltered he started to think about LAM and we planned a research project designed to explore the way lung function altered as LAM progressed. This involved Simon, sometimes with his wife Jan, visiting patients at home, up and down the country, and obtaining information from hospital notes. Simon also started to think about the cellular mechanisms underlying LAM.

Also by chance a handful of patients with LAM from in and around Nottingham were referred to my outpatient clinic for a clinical opinion. One thing which was very noticeable was how isolated these young women felt. In the pre internet era it was virtually impossible to find out anything about LAM, even for doctors, and indeed very little was known. So we decided to invite the women and their families to meet each other at the City Hospital one evening for a glass of wine and a pizza. They found that being able to talk about LAM with other women with LAM was enormously helpful and they left sharing phone numbers etc.

The LAM Trust

In view of this success we decided to contact all the patients in the UK with LAM that Irfan and Simon had identified (now 30) and invited them and their families to meet each other. Eleven patients and their families, 21 people in total, came to this first meeting in Nottingham, on a Saturday in June 1997. Simon and I were somewhat apprehensive since we weren't sure what people would be wanting, so we talked about what was known about LAM and the research we were planning. We left a lot of time for those attending to talk to each other and this again proved to be enormously popular and probably the most useful part of the meeting. One person at this first meeting was Lucy Falconer, American-born but now living in the UK. Lucy had seen one of the emerging LAM specialists, Joel Moss, in Baltimore, and she told us

something about the approach to LAM being taken in the US and the patient's charity there, The LAM Foundation, which had been established two years earlier, in 1995.

At this first meeting in Nottingham in 1997 the attendees made several resolutions – namely to start a self-help group (to be called The LAM Trust), to hold an annual meeting, to start fund raising for research with an optimistic aim of raising £50,000, to start a database with appropriate safeguards, and to have a newsletter. Jane and Brian Ward agreed to write the newsletter, sending out three in 1997 alone and providing an ongoing progress report. By the end of 1997 we had raised £3,500, had a medical fact sheet for patients and the Newsletter contained the first 'LAM Story' - by Yvonne Bates. And, importantly, The LAM Trust was registered as a charity within the Nottingham City Hospital Charitable Trust

The number of people attending the annual meeting slowly increased as word spread, friendships developed and, as an organisation, we gradually became more organized. Joy and Nick Wadsworth took over the newsletter and came up with the catchy name of LAM Post, Teresa Hewat designed our first logo and Jane Ward managed the finances. Clare and Ian Lauwerys used their IT expertise to set up a web site and subsequently an email chat line, LAMline, in 2001 enabling patients to get to know each other better and exchange advice. As one patient Gill Turner commented in LAM Post 'I no longer feel I am the only person who knows what it feels like to have LAM'. Jan Johnson helped informally at first, but then became our first LAM coordinator and a welcoming contact point for queries from patients and particularly for those recently diagnosed. Ideas for raising money now included sponsored London Marathon places, selling Christmas cards and some innovative ideas such as Jonathan Hewat's Auction of Promises', which raised £9,000.

The format of the annual June meeting changed gradually with talks by patients, Q and A sessions and, in 2001, our first

two external speakers who talked about family perspectives (Sandy Raeburn) and exercise and rehabilitation (Mick Steiner). Word about LAM and the LAM Trust spread and by 2001 we knew of 75 patients with LAM.

Our research work had also progressed well and by 2001 we had collated the findings of our surveys and Simon was presenting our findings at scientific meetings in Europe, the US and the UK. We published an article entitled 'Clinical Experience of Lymphangiomyomatosis in the UK' in Thorax in 2000, and I joined the board of the LAM Foundation Clinical Advisory Group. Simon was also developing his laboratory research program and in 2002, thanks to money raised by The LAM Trust, was able to appoint Debbie Clements to help with this.

LAM Developments Outside the UK

The story of LAM in the last 25 years owes an enormous amount to the extraordinary collaboration between patients, doctors and scientists in different countries. For us this started as soon as 1997 when we had some contact with the LAM Foundation in the US, and it gradually extended to other societies and individuals as they contacted us and developed their own self-help groups. Sharing ideas helped us all to improve the clinical management of patients and push the research agenda.



Lucy Falconer with her friend Michelle Gonsalves, chair of FLAM in France

And so to LAM Action

By 2002 we came to the decision that we wanted to be an independent unincorporated charity, separate from the Nottingham City Hospital's Charitable Trust. We also wanted to change our name to the more dynamic LAM Action. This involved a lot of work with the charity commission, spearheaded by Clare Lauwerys, but in 2003 we finally had agreement to be our own independent charity - LAM Action. An executive committee was appointed comprising of Lucy Falconer as chair, Anne Tattersfield deputy chair, Jane Ward treasurer, Jane Tallents secretary, Simon Johnson, Clare Lauwerys, Jonathan Hewat, and Tony Kennett. Teresa Hewat once again updated the logo to reflect the new charity name.



Evolution: The very first logo designed by Teresa Hewat in 1997, the LAM Trust logo designed in 2001, and the first LAM Action logo designed by Teresa in 2003

Overview

Reviewing the 6 years before LAM Action was established in 2003 I'm struck by how much was achieved in a relatively short time. We were lucky in some ways in that Nottingham City Hospital and the University allowed us free use of a lecture hall and rooms for the annual meeting and committee meetings. The Patient Hotel on campus was available for people wanting overnight accommodation, at a subsidised rate. It was lucky for LAM that Simon's asthma project hit the dust and that he turned to LAM for his research and that this turned out to be so successful. The main factor underlying this rapid progress of The LAM Trust however was that the initial patients and their families were incredibly enthusiastic and offered their time, support and expertise so generously. People

with no direct association with LAM (Jane Tallents, Jan Johnson) gave their support unstintingly. And fortunately Simon took to LAM with unbelievable enthusiasm and was able to marry his clinical expertise with his laboratory expertise and curiosity about the mechanisms underlying LAM [more in the next article].

Anne Tattersfield

My thanks to Gill Hollis and Jan Johnson for their comments. The events in the years following the inauguration of LAM Action will be covered in a future article. If anyone has any old LAM Posts up to 2003, could they contact me please at Anne.tattersfield@nottingham.ac.uk.



Jonathan Hewat in charge at the Auction of Promises



Anne Tattersfield, Jane Ward, Clare Lauwerys and Wendy Bishop at an early meeting



Jenny and William's Wedding

Many congratulations from us all at LAM Action to Jenny and William Young, who tied the knot at Piersland House Hotel in Troon on the 16th of April. Jenny and William very kindly raised donations for LAM Action in lieu of wedding presents, and we wish them every happiness for their future life together.

We were originally set to get married in October 2020, but the pandemic meant that we had to change our plans! We always knew that we wanted to help charities that were close to us instead of asking for wedding gifts, and we were delighted to nominate LAM Action.

Jenny's Aunt, **Marion Wiseman**, was diagnosed with LAM back in 2004, and was supported by LAM Action throughout her illness. She underwent a double lung transplant in 2007 at the Freeman Hospital in Newcastle, and this allowed Marion to enjoy more years with her family and friends before her passing in 2011.

We decided to fundraise for LAM Action at our wedding in memory of Marion, and asked family and friends to donate what they could to this charity. It was lovely to see all the donations and kind messages coming in, and, at the last count we had raised over **£1000** for LAM Action.

The wedding day was fantastic, and it was lovely to finally be able to spend time surrounded by family and friends. Marion's son, David, even played the bagpipes as our guests arrived!

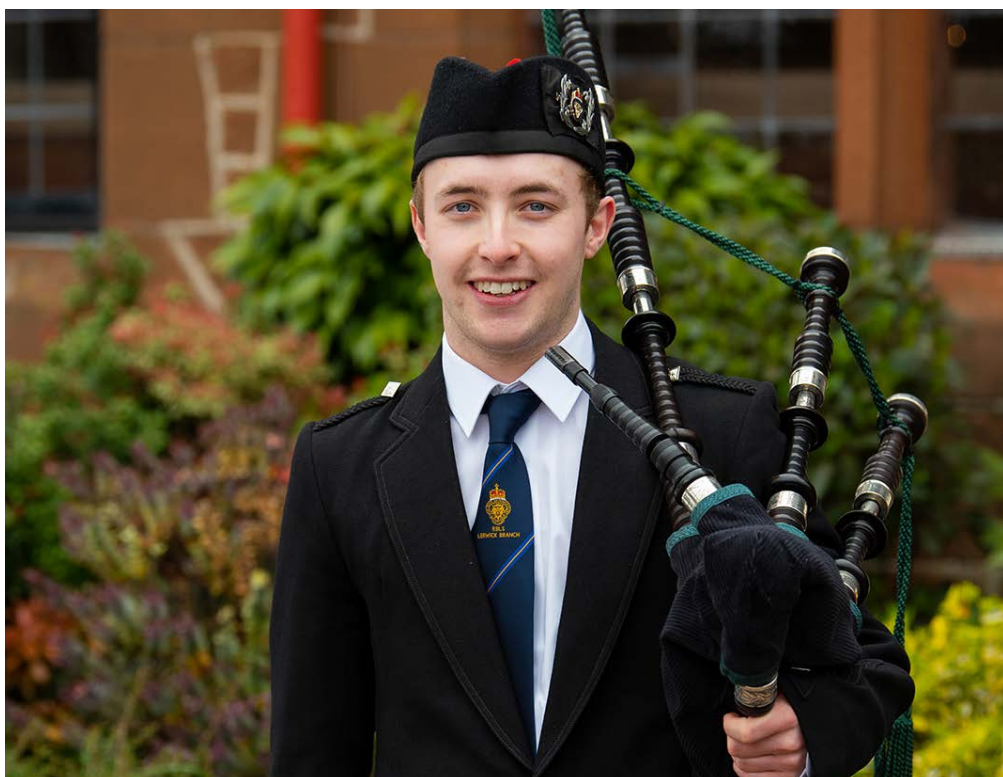
We would encourage other couples who are getting married to do the same as we did! It is a lovely way to help spread even more joy on an amazing day.

Jenny and William Young

<https://www.justgiving.com/fundraising/Jenny-and-William-wedding>



The happy couple with the rest of the wedding party



Marion's son David, who piped the wedding guests in



Me and My Wife (and her LAM)

As a tribute to Nick Wadsworth, we are reproducing the following article which he had written and which was first published in the Spring 2001 edition of LAMPPost.

7:35 a.m. Monday 17th Feb. 1992, after a long night (from roughly 2 p.m. Sunday) our daughter Holly Victoria was born. First job... after a quick clean up... phone work "Hi Mike, Joy won't be at the meeting at 9:30, She's just given birth..." you can imagine the rest.

Thursday afternoon and both mother and daughter are allowed home, wonderful!

However, during the later days of her pregnancy, and particularly since Holly's birth Joy had been feeling increasingly short of breath...

Friday, Joy is really struggling to breathe, and we decide to call our GP, she suspects a pulmonary embolism and we find ourselves back in Stoke Mandeville...

A long afternoon of giving blood for tests, being threatened with warfarin... (which was not administered as Joy was breast feeding!) just in case it's a heart attack/stroke, Joy (and Holly) are detained in the Thoracic ward at Stoke Mandeville. X-rays are also taken and eventually show a

huge fluid build-up around Joy's lungs. The right lung is mostly collapsed, the left partially. Comments passed, whilst quite logical from a medical point of view aren't a lot of help ("Of course its not normal, why didn't you say so earlier?" "How was I to know, I've never been pregnant before, I expected to be short of breath!").

Fortunately, we were lucky in that one of the consultants at Stoke (Williams the chest) had experience of another patient with LAM (sorry Lucy) and Joy was soon diagnosed with the condition.

However, due to the nature of the chylous effusion Joy was suffering, a transfer to the Radcliffe in Oxford was necessary to close up the split lymph duct in her chest. Eventually Joy had open chest surgery to fix the split lymph duct and was then put on a strict 'no fat' diet to try to reduce the production of chyl. This may be great for the figure, but it isn't so hot for the digestive system (not much lubrication). During her period at the Radcliffe Joy was given the one instruction that distressed her more than anything, she was told she must stop breast feeding Holly. She was losing so much protein, fat, and fluid in the effusion that she simply could not feed both herself and her daughter. As a member of NCT, realising the importance of early breast feeding, this was a real blow and it took a good three days of persuasion for her to see that it was for the best.

After a week or so Joy was transferred back to Stoke, and as she desperately wanted to have Holly close by, we were offered a side room in the maternity ward. Joy was of course kept under close observation and a course of progesterone treatment was suggested to stabilise the condition. (Holly, at 9 has finally shaken off these early experiences, she now takes ages to eat her dinner, for the first 6 to 8 weeks whenever she started to feed some 'nasty man' would appear and interrupt her lunch, demanding mummy for tests, or blood, or something, so food when offered vanished very rapidly, just in case!)

Joy's condition was stabilised and she was allowed home around Easter. We were advised by the consultant not to be too taken in by the medical literature of the time as a lot of it did not take into account any recent developments in the field, but you just have to know and, since this was the early days of the web, we enlisted the help of a friend to dig out any medical reference articles on LAM. What depressing reading... at least Joy has beaten the predictions in those articles by 3 years already!

Since diagnosis Joy has been on progesterone injections, initially every month, then 2, then 3, then 4, now 6 monthly, so far, she shows no sign of deterioration in her lung condition, and she is working full time as a teacher. Holly is fine.

My only observation from the side-lines, so to speak, is that I would like to see some research into the psychological effects of the progesterone treatment, as it appears, to a 'poor' uneducated engineer like me that given the known mood swings of many women over their monthly period these injections must cause some emotional complications. I have certainly noticed differences with Joy, and at 40 I would not expect them just yet.

Finally, I would like to thank all the medical staff involved... I still have a fine wife, a wonderful daughter (don't tell her that) and although the future is not certain, at least we know there are others in similar situations.

Keep up the good work!

Nick Wadsworth

LAMPost Needs YOU!!!



The last few editions of LAMPost have seen a drop off in content and articles generated by our readership, and we have had to rely more on content from current and ex committee members. We recognise this is probably due to the fact a lot of our readers have had to curtail many of their activities due to the pandemic, but now things are starting to return to normal, we could really benefit from a few new and different voices to help us create an alternative direction on what makes up the newsletter going forward.

We would really like to hear more from YOU, our readers, and you can help us immensely by writing something for us and creating the agenda for yourselves. What would you like to see covered in future editions? Why not take the bull by the horns and write it for us!

We are always very grateful for all contributions received, on any subject that you think our readers would find interesting or useful. If you don't feel comfortable writing something yourself but you have an idea or suggestion for an article then please do drop us a line, similarly if you have any feedback for us or simply to say hello, we are always delighted to hear from our lovely readers!

lampost@office.lamaction.org

Best wishes, the LAMPost Team

The next edition of LAMPost will be out just before Christmas 2022 with a deadline for submissions of **November 30** - thank you!

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