DECEMBER 2021

LAMPost

LAM ACTION
Supporting women with
Lymphangioleiomyomatosis

It’s beginning to look a lot like Christmas...

From the Editor's Desk

It only seems like yesterday that the clocks went back, but as we go to press we have just gone past the winter solstice so we can now look forward to the evenings becoming incrementally lighter. I am reminded recently of the strapline for the film Jaws 2: 'Just when you thought it was safe to go back in the water' with the emergence of the latest Omicron variant of COVID-19 - just when we thought it might be safe to get back to some sort of normality, this comes along. While it remains to be seen just how sharp toothed Omicron might be, the forecasts are not looking good currently and we hope that this edition of LAMPost finds all our readers safe and well, and looking forward to the best Christmas possible in these continuing uncertain times.

Everyone at LAM Action sends their congratulations to LAM Action-funded researcher **Dr Debbie Clements**, who recently won the Wendy Stannard prize for best oral presentation. Debbie presented her LAM research to over 120 researchers and clinicians in the East Midlands at the Joint Respiratory Research conference held at the Leicester Tigers rugby club on Thursday 11th November. Well done Debbie, we are all very proud of you!

While charities across the globe continue to be hit by a slowdown in fundraising we are still very grateful for all the smaller yet vital fundraisers on our behalf which ensure that we can keep funding researchers like Debbie.

A couple of recent examples are **Carmel Rycroft** who asked for donations instead of gifts for her birthday which raised £176 and just this week **Di Collins** has set up a birthday Facebook fundraiser to help us as well - thank you to everyone out there who has helped keep the funds ticking over in yet another difficult year.

The new website sub-committee have been extremely busy working on the new site and they are hoping to release the new version very shortly. As you might expect there will be some snags and things to correct after release so please bear with them and all feedback on the new website will be very welcome.

We were all deeply saddened to hear of the passing of **Justine Laymond** on December 7th. Justine had received a double lung transplant at Harefield Hospital in 2006 and since then had lived life to the full and her effervescent personality will be greatly missed by all who knew her. Gill Hollis has written a lovely tribute to Justine on the following pages.

We will hope to be back again in the Spring of 2022, with a publication deadline of March 31st, please email any articles or other contributions to: lampost@office.lamaction.org.

Until then please stay safe and well, and the LAMPost team send their best wishes to you and your loved ones for a lovely Christmas, and a happy and healthy New Year.

John and Francesca

Join the Spotty Sox Gang!

Joan Mensor is back again with one of her delightfully dotty nonsense poems, this time inspired by her recent trip to the LAM Centre where she discovered that her and Professor Johnson had something unusual in common!

Joan said: “After an excellent consultation with Professor Simon Johnson I was inspired to write this nonsense poem as Professor Johnson was wearing spotty socks, and I had just bought some myself, and it sparked a little moment of humour between us. I in no way mean to disrespect him, as like all Lammies we hold him close to our hearts for all that he has done for us, but wearing such socks shows his humanity I think. So here it is:

Join Our Gang

Are you a member of the Spotty Sox Gang?
I am and so is Professor Johnson of LAM!
Such adorning of your feet at the dawn of each day
is a wonderful way of chasing away
all those SAD winter blues,
so you’ve nothing to lose.
Choose socks with brightly coloured spots on,
in fact it’s clear that it’s odds on
they could change your life
with no trouble or strife.
So roll up and join us,
all are welcome, don’t be afraid,
just sign up as members
of the Spotty Sox Brigade!

Joan Mensor


2009 LAM Action meeting, Essex Girls – Justine (centre) with Clair Hemmington (left) and Clare Lauwerys (right), who all lived in Essex and received lung transplants at Harefield.

Remembering Justine Laymond

Many people in the LAM and transplant communities knew Justine Laymond, who passed away on 7 December. Justine received a double lung transplant in 2006, and had been fit and well until catching COVID in mid-November. Exuberant, colourful and never, ever boring, she was an early adopter of social media, which she used to chronicle both her health challenges and post-transplant adventures. She entertained and inspired her many followers, while raising awareness of LAM and transplantation along the way.

Justine's family first contacted LAM Action in 2005, when she had just been diagnosed with LAM after 10 years of symptoms. By then, she was very unwell and was put on the transplant list almost immediately. After a wait beset by serious health complications, she finally received new lungs at Harefield Hospital in July 2006. In the years that followed, as Prof. Simon Johnson of the National LAM Centre said, "Justine certainly made the best use of her new lungs".

As soon as she had recovered from transplant surgery, she built up her fitness and started participating in fundraising runs and competing in the Transplant Games. A regular at the UK Games, she also attended European and World Transplant Games in Sweden, Australia and South Africa, accumulating a haul of medals and many friends. At home, she became a regular at her local Essex Bootcamps.

If these adventures were not enough, Justine also signed up for two challenges which even the most fit and healthy of individuals would have found gruelling. In 2012, she sailed across the Atlantic on the final leg of the Clipper 11-12 round-the-world yacht race, under an initiative in which 10 medic and patient “transplant ambassadors” sought to demonstrate what can be achieved by transplantation. And in 2015, she joined an expedition arranged by the Harefield transplant unit in which a group of people who all had had heart or lung transplants attempted to summit a series of high-altitude volcanos in Ecuador.

Justine was very artistic, and painted as LAM lung artist. In recent years, she reinvented herself again, this time as a stage performer under the stage name L’amour Le Monde. Notably, she developed a burlesque routine based around her life story, which reflected her LAM journey and celebrated her post-transplant life. More recently, she expanded her repertoire and on her L’amour Le Monde websites she described herself as an “international neo burlesque drag artist, and a wig and make-up stylist”. These words do not do justice to the amazingly beautiful and colourful looks she modelled on her social media pages.

The many faces of L’Amour Le Monde (credit L’Amour Le Monde)

With her effervescent personality, flamboyant style and compelling stories, Justine was a media favourite, regularly featuring in newspapers, on radio and on TV. But she was also adept at harnessing new media to tell her story and raise awareness of both LAM and transplantation. On her blogs and social media accounts, she chronicled all her health challenges and post-transplant adventures openly and honestly. As a result, she inspired and entertained followers and friends amongst the LAM and transplant communities around the world.

She never forgot her underlying lung condition and her connection to LAM Action. Our 2009 annual meeting was attended by seven women with LAM, including Justine, who had received lung transplants between 2004 and 2009. The celebratory mood was captured in the photograph below. It's worth pointing out that this was a year before sirolimus was shown to be an effective treatment in slowing or even stopping the progression of LAM in most patients. One of the most obvious indicators of the success of sirolimus in treating LAM is the steep reduction in the numbers of women being referred for transplant by the National LAM Centre. But for those who needed it, lung transplants saved our lives.

2009 LAM Action meeting, 7 women with LAM who received lung transplants between 2004 and 2009

Justine also raised funds for LAM Action on many occasions after her diagnosis, most recently with her partner Tom in 2020. They set a challenge of walking the distance of a marathon each week for the month of July. 117 miles later, they had raised an incredible £4,760 in conjunction with Tom's workplace, Gallagher Re, for which we were very grateful.

Justine and Tom on their "Marathon a Week for a Month" fundraiser for LAM Action (credit Tom Hipperson)

In what turned out to be her final post, Justine asked that people "...please keep my memories alive". If you would like to read more about Justine, please look at her social media:

Facebook – Jussie La Mode
https://www.facebook.com/justinedoublelungs

Facebook – L'amour Le Monde
https://www.facebook.com/LamourLeMondeJustine

Instagram – L'amour Le Monde
https://www.instagram.com/lamourlemonde/

Blog - **http://justinedoublelungs.blogspot.com/**

Tom has also set up a tribute page to Justine at **https://jussie.muchloved.com/**

Tom came into Justine's life 8 years ago and theirs was clearly a blissfully happy relationship, one that has ended far, far too soon. Our thoughts are with Tom, Justine's mother and brothers and her many friends.

Gill Hollis, LAM Action

Reaching for the stars

For most people, turning 60 would mean time to slow down a bit and put their feet up a bit more. Not for Joy Wadsworth though, here she tells us how her 60th birthday was the cue to becoming fitter and more active.

This year, I turned 60. I decided I didn't want to be this old so I set about getting fitter and losing weight. At the end of 2020 I was struggling on 4lpm pulse when walking so I went for a re-assessment at my local respiratory unit. As a result, my oxygen was increased to 6 to 8 lpm continuous for exercise. This meant new portables for my LOX as a Marathon does not last long on 6lpm continuous.

In January I signed up for Walk 1000 miles 2021, through Country Walking magazine. In order to complete it I needed to walk an average of 2.69 miles a day and for the first part of the year I managed this by walking a 3-mile circuit of my village several times a week. Holidays in Devon and Yorkshire gave opportunities for longer walks but in autumn things started going downhill. Currently (at the end of November) I'm at 826 miles so I'll need to do about 35 miles a week from now on which is unlikely to happen.

I've been going to the gym for several years now but during lockdown they put on Zoom sessions for members. I changed my personal trainer during that time and, now we are back in the building, I'm having a PT session and two solo sessions each week. It has definitely improved my fitness even if my liking for cake has meant that I'm not losing the weight I should.

In August, my challenge 60 was to start climbing again. I go to Warwick University climbing centre in Coventry where I can climb using a harness and auto belay (a pulley system that will allegedly catch you if you fall) as well as bouldering which is basically scrambling with deep mats underneath but no ropes. I try to go once a week and am gradually getting better although I still haven't reached the top of any of the roped climbs. The pictures show how I use my Marathon with a short cannula tube. I thread it out of the bottom of the backpack and up underneath my tee-shirt so that it doesn't catch on anything. On 6lpm continuous, it only lasts about an hour and a half but I'd struggle to climb for that long. I use a single tube rather than the double tube usually used with a Marathon because oxygen only comes out of one nozzle (the other is just the trigger mechanism for pulse delivery) and the single tube means that it goes into both nostrils instead of just one which is more comfortable.

Another challenge this year was to take part in NaNoWriMo where you sign up to write 50,000 words in the month of November. Due to various things, I haven't achieved the 50,000 words but I have worked on my novel and I plan to continue with it.

My birthday was at the beginning of November and I took my daughter and one of my sisters for a spa day. It was a lovely, relaxing day and I even managed to do some swimming without my oxygen!

So how has my challenge 60 been? Well, my metabolic age is still older than I'd like and I tend to suffer the gym rather than enjoy it but climbing is fun and the other week I was invited to join a ladies' coaching night which was really good. I'm moving my gym membership to the university and in the New Year I intend to try a bit of swimming along with some spin classes.

Joy Wadsworth


HELIOS

Runners & Riders Required!

As we head into 2022 many of us will look hopefully towards lighter evenings in Spring and the chance to get out and exercise. LAM Action can help provide motivation for that with a range of fundraising events that might be just the thing for you or your friends to train for and take part in.

If you are into cycling, Ride London on 29th May is a 100-mile cycle from Victoria Embankment through the leafy lanes of Essex before finishing in style on Tower Bridge. Last time it was held over 80,000 people applied for places in the ballot and most were unlucky, but LAM Action has guaranteed places available for anyone who is prepared to fundraise for the charity. Our target for each rider is £300 and in return you will receive a LAM Action cycle top and all the support we can muster with fundraising and on the day.

And for keen runners, we can virtually guarantee places in most of the big events that take place around the country, with access to marathons and half marathons, 10ks and 5ks anywhere from Edinburgh to Bath and Belfast to Brighton. Whether it is the Great North Run or the Royal Parks Half marathon, if you or a friend has an event in mind just let us know and through a link with Run for Charity we will do our best to find places.

On 3rd October the London Marathon provides a fitting climax to the running year, following an iconic route past London's landmarks and finishing in front of Buckingham Palace. LAM Action has a number of charity places up for grabs, with runners aiming to raise £2000 in sponsorship, and supporters out on the streets and at the finish to say "Thank you" to all our participants.

Over the last couple of years COVID-19 has severely restricted charities' fundraising activities and LAM Action is no exception, so please have a think about events that you or your family and friends could do. Training for the big day and then taking part has proved a life changing experience for many of our fundraisers and the money raised goes towards support for women with LAM and research to find a cure.

For more information, please contact David Mercer on 01306 731466 or e-mail
david.mercer@office.lamaction.org

David Mercer

A very big thank you and well done to **Tom Archer** and **Lucas Meagor** who ran the 2021 London Marathon in support of LAM Action on October 3rd.

Lucas made a valiant effort in his attempt to break the world record for the fastest time for a phone box, but running into a headwind from mile 15 was not ideal, though he still posted an amazing time of 4 hours 33 - as well as being interviewed live on air by the BBC. With Gift Aid, Lucas will have raised over **£5,555** for LAM Action.

Army veteran Tom Archer came storming home in a very quick time of 3 hours and 7 minutes, Tom is a family friend of LAM Action Chair Leanne Lillywhite-Sutton and he raised a great total of **£1,6700** for us.

Thank you both so much for supporting LAM Action and congratulations on your amazing fundraising!

Healthy eating - help is at hand

Tina Dickinson recently faced the daunting prospect of having to lose weight, and to eat more healthily. After doing some online research she found a very useful NHS programme that has helped her immensely and she is now reaping the rewards.

I knew I had to lose weight, but I also knew diets just didn't work for me. There are so many foods I don't like I just couldn't stick to anything. I've done Weight Watchers, Rosemary Conley and Slimming World but food just bores me. I hate cooking. After putting on weight over lockdown and after having a few heart blips I was still just told "you need to lose weight".

My friends know me as Mrs Google, and all give me things to find for them on the internet. So, I hit Google with searches like "losing weight healthily, eating healthily, ways to learn about food" etc. On one page I found something called NHS Diabetes Prevention. I thought well I'm not diabetic, but it may have food suggestions on it. I clicked on it and it asked a few basic questions then it told me I was eligible for the NHS Diabetes Prevention programme.

I honestly expected the usual diet sheets, menu suggestions, recipes etc and it said you needed scales which I didn't have but I thought OK let's buy some and give it a go!

I had a 1 to 1 chat with someone on the phone and received an email with a 9/12 month programme. For the first 3 months I had fortnightly online training in a group of around 8 people. It then went to 4 weekly sessions. The sessions included pre diabetic people, people who needed to lose weight and people who needed to put weight on. We learned about portion plates, how carbs turn to sugars, how your body works, what exercise does, how your liver processes sugars, what to look for on food labels etc. etc. I haven't given anything up that I love but I have learned what my body needs.

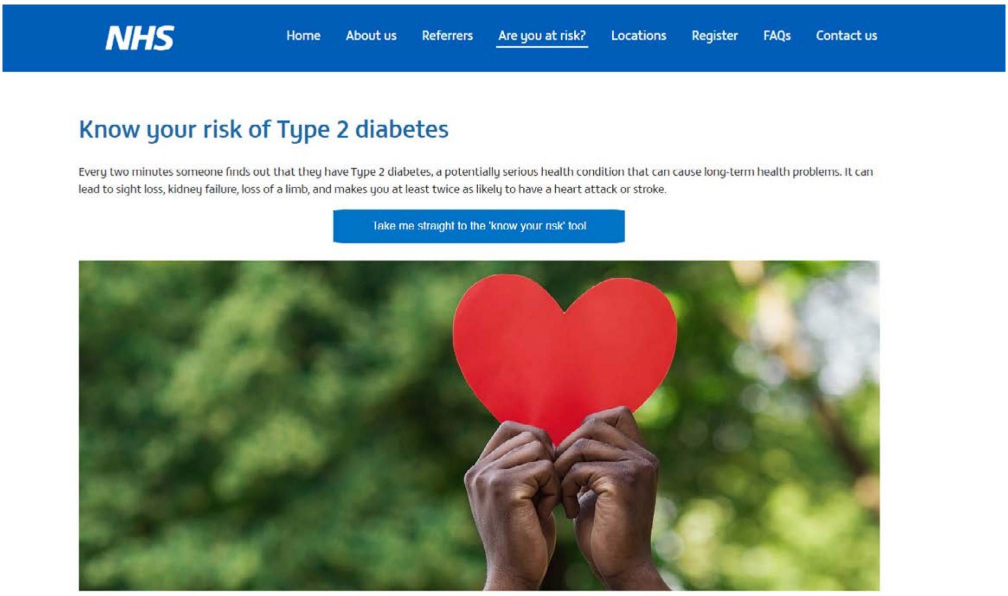
I'm on month 7 and I've lost 2 stones 1/2lb.

If anyone is struggling to eat healthier, lose weight or put weight on, I can highly recommend the programme. Apparently, it's not available in every area of the UK but it is available in lots of areas and for people like me who hate cooking and don't want to give up all the nice stuff it's great.

For more details about the programme please visit:

https://preventing-diabetes.co.uk/Know-your-risk-dtc/

Tina Dickinson



Know your risk of Type 2 diabetes

Every two minutes someone finds out that they have Type 2 diabetes, a potentially serious health condition that can cause long-term health problems. It can lead to sight loss, kidney failure, loss of a limb, and makes you at least twice as likely to have a heart attack or stroke.

Great fun for all the family

Fir-m Favourites

Sally and Ron once again opened up their Christmas Tree field so that people could cut their own trees in return for donations to LAM Action. This proved to be hugely popular once again with people coming from far and wide to bag their lovely trees. With sterling support from Sally's sister Louise, their friends Lesley and Mike, and also Helen Humphrey who provided a raffle and also some amazing Christmas wreaths, they have once again raised an absolutely fantastic amount of just over £6,000 including proceeds from the wreaths and raffle, which with Gift Aid will make over £7,000. A big thank you to Sally, Ron, Louise, Lesley, Mike and Helen as well as everybody who supported us and we hope your trees help to make your Christmas that little bit extra special!

Strap it down and the job's a good 'un

Bagging the perfect trees


The lovely wreaths made by Helen Humphrey


It's not that warm mate!


Barking up the right tree!


More happy customers


We're going to need a bigger car...


... but where there's a will there's a way!

Ron (left) helping to carry
the biggest tree cut this year

Always time
for a cuddle

Lesley with one
of the lucky
raffle winners

Did we bring a compass?

The next edition of LAMPost will be out in Spring 2022 with a deadline for submissions of **March 31** - 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

LAM ACTION
Supporting women with
Lymphangioleiomyomatosis