

DECEMBER 2023

LAMPPost

LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Tee-ing Up a Great Fundraiser

From the Editor's Desk



Where on earth did 2023 go? It sounds a bit of a cliché, but it really does seem that the older you get, the quicker time flies and it seems like only last week that I was putting the finishing touches to the edition that was published just before Christmas last year.

January and February always seem so bleak with not a great deal to look forward to, but this February it will be time to get your glad rags on and let your hair down as love is very much in the air! Big thanks to **Helen Sabin** and her good friend **Pinky Sidhu** who are organising a Valentine's Ball to raise funds for LAM Action. The ball will be held in Leamington Spa on **Saturday 10th February**, full details can be found on page 18, and we hope there will be lots of takers for what promises to be a wonderful evening and a good excuse to shake off the post-Christmas blues!

We have an absolute Christmas cracker of an edition this time round. As well as the usual fundraising highlights we have two fascinating and inspirational articles from ladies with LAM, both accompanied by some stunning photos. At the end of November I was scratching my head and wondering how on earth I was going to fill the pages, but as always it all came together in the end and I am hugely grateful to everybody who has contributed to this newsletter.

The Committee were delighted to welcome a new member recently when **Adam Davidson** joined us a Trustee. You can read all about Adam on the following pages and he was rather thrown in at the deep end as his first interactions with the rest of the Committee

came in November at our Strategy Day, which you can also read about on page 19. Welcome on board Adam!

As you will see, our fantastic fundraisers have been very busy of late, raising valuable funds for LAM Action and we are constantly astonished at some of the innovative and varied ways that people have found to support us, and we send huge thanks to every one of you out there. Just a quick reminder that if you are planning a fundraiser, please get in touch with Jill, as there are many ways that we can help your event come to fruition.

LAMPost will return in the spring, with a publication deadline of **April 5th**, please email any articles or other contributions to: lampost@office.lamaction.org.

Until then please have yourselves a merry little Christmas, wherever in the world you may be, and very best wishes for the coming new year.

John



Season's Greetings

BEST WISHES FOR THE
FESTIVE SEASON AND FOR A
HAPPY AND HEALTHY NEW
YEAR FROM EVERYONE AT
LAM ACTION

LAM ACTION
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Adam and Harriet getting muddy to raise funds for LAM Action

Introducing Adam Davidson

Hello, my name is Adam and I have recently been welcomed as a Trustee here at LAM Action. My link to the charity is that my wife, Harriet, is a LAM patient, and I would like to work with the existing hard-working Trustees to maximise the effectiveness of the charity.

A little about me... I love sport, and I'll watch almost anything! But although I am more of an armchair follower now, I do still swim competitively in the Masters category. I volunteered at the Birmingham Commonwealth Games in 2022, and during this event, I met the now King and watched the 1,500m swimming heats with the Prince and Princess of Wales (it's not a popular race and they needed 'seat fillers' for the cameras!!).

I have previously raised money for LAM Action with my wife Harriet, and also with my former swimming team (Birmingham Masters). I also supported Harriet in 2022 by attending the LAM Foundation's LAMposium in Chicago and spent time volunteering on the merchandise table. This was an amazing event, both socially and educationally, and I would 100% recommend attending should you have the means to do so.

My career is as a development surveyor, focused on encouraging housing development through the regeneration of brownfield land. I completed a quite major milestone in my career this year, through the completion of a master's degree. I've had quite a busy year really, having moved to a new city (from Birmingham to Bristol), embarked on a master's degree, got married (in February), honeymooned in Italy, started a new job, and joined LAM Action as a Trustee.

I am really excited to become fully involved with the operation of the charity and to ultimately support and benefit patients and their families as per the overarching goals of the charity.

Adam Davidson





That's What Friends Are Fore!

All of us at LAM Action were delighted when we learned that we had been chosen as the Captain's Charity at Aldenham Golf and Country Club, just outside Watford in Hertfordshire. The reason we were chosen? My best friend Simon has just taken over the captaincy there!

I have known my best friend Simon Veysey since we were 9 year olds, meeting on my first day at school in Bushey after moving down from Scotland in 1975, and we have been best friends ever since. So when Simon became Captain of his local golf club, there was only one charity that he was going to support.

It was a bright and (very) early start on Saturday October 28th. I arrived at the club at 07:15 and already it was a hive of activity. Club Treasurer Ian Mackie and Simon had already been busy taking competition registrations and entry fees, while Kate Savage was doing a sterling job selling raffle tickets. All proceeds from the day's competitions and raffle would be going to LAM Action - the start of a whole year of fundraising for us that will culminate in July next year with the Captain's Charity Golf Day.

After all the registrations, the club members started heading outside to tee off. Aldenham General Manager Bradley Potts had set up the 'Halfway House' gazebo on

the 10th tee, and the catering staff had filled a couple of hot serving plates with both meaty and vegan sausage rolls and they would be kept busy topping these up throughout the morning as there was a steady stream of hungry golfers coming round, having completed the front 9 holes. Tea and coffee were also available and the Captain had also provided beer, whisky and prosecco for those looking for something stronger.

My wife Sarah and I were manning the refreshment tables and there were many tales of woe from some of the golfers who had fared less than spectacularly on the front 9, however after a tot of whisky at the Halfway House we witnessed some near perfect drives down the 10th fairway so maybe that is the secret to having a good round!

We also took some very generous donations from the players who were keen to support the charity by depositing some notes and change in the collection bucket next to the sausage rolls.

Towards the end of the morning the skies began to darken ominously and it wasn't long before some heavy rain swept in, though it didn't last that long and the sun came back out. Little did we know that this was just the gentle introduction to what was to come later. Simon had almost finished his round and was coming down the 18th fairway when the heavens opened with some epic rainfall more akin to a Biblical flood. We abandoned the gazebo and made a run for the clubhouse but still got absolutely drenched and even the money in the collection bucket had to be dried out later as so much water had poured in through the slit in the lid.

One of the competitions was the 'Captain's Drive In' where participants paid £5 to predict where they thought Simon's drive from the 1st tee in the afternoon would end up, writing their names on small white pegs which they placed on the 1st fairway. Traditionally, this is always done by the Captain wearing fancy dress and this year it was a Christmas theme with a Santa and Elf costume. Amazingly, he still managed to hit a decent shot off the tee!

All in all a very fun (and wet!) day was had by all, and approximately £1,000 had been raised for LAM Action by the end, a fantastic amount and we know that Aldenham Golf & Country Club are going to continue to do us proud throughout the coming year of Simon's captaincy.

If any LAM Action supporters would like to play in the Charity Day on July 13th 2024 then please let us know, and we can make arrangements for you to attend.

John Wood




**Aldenham Treasurer
Ian Mackie with Simon
Veysey and Kate Savage**



**The LAMPost
Editor with Simon
on the 10th Tee**



A photograph of Deborah, a woman with grey hair and glasses, standing behind a large outdoor stall filled with various knitted items. She is wearing a grey patterned top and a yellow bag. The stall is covered with a white cloth and displays a wide variety of colorful knitted goods, including hats, scarves, gloves, and small stuffed animals. In the background, there is a brick building with windows and some outdoor furniture like orange chairs. The scene is set outdoors on a grassy area.

Deborah with some of the lovely knitted items for sale

Getting Stitched Up for LAM Action

Big thanks from all of us at LAM Action to Deborah Kamis-Murphy who organised a fête to raise funds for us on 31st August at The Christopher Pickering Lodge in Hull which raised over £2000, an absolutely amazing amount!

Deborah said: "It was a great day and the weather was amazing.

I run a knit and natter group for the elderly and we have been busy all year making things for the stall. I had four stalls for the knitted items, a cake stall, tombola and a bottle tombola and I invited other small businesses to join us.

I also had a raffle: the main prize was a hot tub kindly donated by the daughter of one of my knitters, and the local people came out to support us.

I am struggling with this disease as well as fibromyalgia. I know that there are a lot of women out there also struggling with this condition and trying to understand and come to terms with this dreadful disease. I am so glad that I have been able to contribute towards the research and look forward to my next fundraiser."

Thank you to all your knitters Deborah, and to all the local businesses that supported your wonderful event!



News Roundup

Annie Sekowski

The LAM Action Committee were very sorry to hear that one of our longer-standing LAM patients in the UK, **Annie Sekowski**, died in September.

Annie lived in Nottingham and was a trustee of LAM Action between 2010-2013. She leaves behind her husband, Mike, and their adult son Jonathan, and our thoughts are with them, and their friends and wider family.



Allison Hamilton and Simon Fairbrother

Two of our stalwart fundraisers have been busy putting themselves through the pain barrier once again for LAM Action.

Allison Hamilton is a partially-sighted runner who has competed in many half marathons around her native Glasgow and was back again at the Glasgow Great Scottish Run 10k on 1st October.

Allison said "There was a great atmosphere as usual, and the weather stayed dry. I had been unwell a few weeks ago and hadn't been able to train as much as I would usually do for various reasons. So I really struggled, especially the

last few kms. My friend and running guide, Liz Deans, kept me going and another friend, Catrina, helped me reach the finish line.”

Simon Fairbrother is a 2 time veteran of Ride London, though on this occasion he was using his legs instead of wheels, completing the Royal Parks Half Marathon on 8th October in aid of LAM Action.

Big thanks to you both for supporting us once again!



Cheque it out!

As featured in the Spring 2023 newsletter, we were delighted to be presented with a cheque for £800 which had been raised at the 13th Elysian Beer Festival back in April. A very big thank you to the Ely branch of CAMRA and to the Larwood family for your wonderful fundraising on our behalf.

[L-R]: **Ali Hulbert**, LAM Centre Nurse Specialist, **Wendy Somerfield**, LAM Centre Co-ordinator, and **Karen Larwood**





Taking the Long Way Home

I was diagnosed with LAM just before my 30th birthday or was it just after...

It's hard to remember now I'm 57. My experience of the disease has been slow progression which means I am able to live normally but I'm aware the journey is not the same for all of us.

The first inclination I had the disease was at the age of 25 was when I had my kidney removed because of a malignant tumour. It was never connected to any disease, that came when little cysts were spotted on the base of my lung, during my 5-year check when I thought I was going to be able to hit a bell or something and run out the door elated.

Instead, in the follow up I got a lovely letter from my dear urologist Mr F, saying let me introduce you to my very good friend and colleague, Dr G who is a Respiratory specialist.

When the LAM diagnosis came, I took it bizarrely in my stride even though a prognosis of 10 years was mentioned. The first shock of mortality had already hit me at 25 and at 27 I had begun living life to the maximum. I'd left a job, gone to university, learned to drive, left a marriage, learned to swim and begun to look beyond my horizons at the world beyond my doorstep, eager to soak it all up before my demise.

So here I am @ 57 thinking oops, now about that pension plan.

We never know when life will chuck rocks in front of our path. I have developed resilience; patience, importance of who I surround myself with. I've learned that looking after my own health and well-being is a priority but sometimes life events see me push it to the backburner. I have learned things about myself; things that I don't discuss because I've learned with this disease the art of the 7-day wonder. For 7 days everyone is aware and then interest subsides and I am alone with my inner sense of being and I've learned through meditation and kindness to myself that that's really okay. I know my strengths, my weaknesses.

I've taken risks, I was also aware of the risk of a pneumothorax when flying and reminded of it, then asked where you have been this year. It would be followed by a list of weird and wonderful places from around the globe. I was very lucky.

However, like a boulder suddenly along came a deprivation of all those opportunities when COVID-19 came our way and suddenly all my gregarious spirit left me and I was placed on a list of clinically vulnerable people along with my LAM sisters. I call you sisters because your strength and determination on each of our very different paths inspires me daily to keep going. I have met some of you, know many of you or have followed you and I have learned that each one of us has a different journey.

So COVID brought new things to my door, fear, anxiety, loss of confidence, sense of hopelessness, fear of crowds, busy spaces, travel, socialising and the aftermath hung on. All things I've never felt at least not all at once. I'd be lying to say for a couple not ever. Fear, anxiety come with any health diagnoses.

In 1997 soon after I was diagnosed, I travelled to Spain and taught English in a Basque school in San Sebastian. I arrived knowing no-one. I met some Brits doing similar

and then I stayed with a Basque family. I was me without labels with LAM but without anyone else looking at me with a sympathetic stare or look.

I was able to be me in a way I hadn't been in 6 years since the kidney op. Free and at one with myself in a country that welcomed and nurtured me and always has done since when I step on its turf.

In September of this year, after a bit of planning I decided that I needed to go there to hit the reset button once more. An inspirational friend, the one who encouraged me to go to Spain even though she never realised it till this year had completed el Camino Portuges and was about to embark on el Camino Frances.

I had learned about these pilgrimages not just from the Martin Sheen movie, 'The Way' but when I lived in San Sebastian and El Norte which is on the 60th birthday goal plan was the first one I'd heard of.

So I booked and off I went. It was like going home. Astorga – Santiago de Compostella. Approx. 300 km in total in 12 days and when I hit the end of the journey I wept with joy. It was like being free and in the arms of nature and a people who showed nothing but kindness. It was the soothing arms and love I needed to remind me of all that I am, all that I was and all I can be.



Some days were challenging. Sometimes it was the head that was the challenge. The thought of a steep incline and how the lungs or I would cope. The fear and anxiety in anticipation but followed with the adrenalin when completed.

I didn't train for weeks as some had. I did train a little but in my head I wasn't on a race. Others were, they were smashing their kilometres before they'd smash their avocado, oblivious of who or where they'd just passed or been. I'd made a pact to myself, just like I did when I ran the NYC marathon, it wasn't about smashing records, just being there was record in itself.

If I needed to catch a bus I would or a taxi or flash an old wrinkly leg to catch a lift. Whatever, it wasn't going to be a race, it was the time to be, to be at one and to be at peace.



So what was it all about:

It was an appreciation of the simple things, friendship, the art of conversation, the exploration of souls and us, appreciation of nature, simple food, good wine and being at one in your own mind without the negative influences that surround us in our daily hectic lives in a world that is continually adapting and changing, not always sadly for the better.

No social media, no work emails, strict news coverage, no lost time gazing at a screen admiring someone else's wedding I don't even know, just me and those that surrounded where we followed: Eat, sleep, walk, think, don't think, repeat.

It was the reset button I needed and whilst the external forces still come in on my return, I have reminded myself that I have the inner sanctuary of self to go to surrounded by nature. Galicia was like Glasgow where I've returned to in the full circle way of life, misty, mirky and even had full blown heather so when I'm out I can take my imagination back to the place that heals my soul but equally realise that in being home, I am already there. The people of Glasgow might be loud but they are passionate but fundamentally most of them are kind and I've realised that kindness is the key to life we all need but kindness to self, most of all.

Karen Swift



Love is in the Air!

Valentine's Ball

Valentine's is usually associated with hearts
but our Ball is all about lungs!

We are fundraising in aid of LAM Action who
support women with the rare lung disease
Lymphangioleiomyomatosis (LAM)

Venue: The House & Orangery, Newbold
Terrace East, Leamington Spa, CV32 4EU

10th February 2024

6.30pm - Midnight

£55 per ticket

(includes a drink on arrival, 3 course
meal and music & dancing)

There will be a raffle and auction plus
some entertaining games. If you wish
to join in with the games please
bring a little bit of cash with you!

To purchase your tickets please contact
Helen Sabin on 07545 459250
Or Pinky Sidhu on 07581 173817

Dress Code:
Black Tie



LAM ACTION

Supporting women with
Lymphangioleiomyomatosis



Registered Charity 1167610
(England and Wales)



LAM Action Strategy Day

LAM Action in action (L-R): **Simon, Leanne, Harriet, Adam, Kelly, Ilona, Gill, Jo, David, John and Sally**

It was a case of 'lovely to see you again' when the LAM Action Committee met in Nottingham on November 17th, the first time we had (almost) all been in a room together since before the pandemic.

This was no ordinary Committee Meeting however, as we had been trying to arrange a 'Strategy day' for some time, where we could take stock of where we have come from as a charity, where we currently are, and to tackle the thorny issues of where we would like to go in the next five years as well as what changes or additional resource we might need to enable us to get there.

A fascinating day ensued, with lots of brainstorming, interesting debate and food for thought going forward. Rest assured it's not all about us and we will be reaching out to the UK LAM community in the new year to also get your thoughts and valuable insights, so please stay tuned!

Thank you to **Kate Burrows** who expertly facilitated the day and kept us from wandering off at tangents!



(L-R): His Excellency Sir John Lorimer, Rachel Moore, Anna Kerruish, Anna's Dad Keith

Ticking All the Boxes for a Lovely Donation!

Anna Kerruish, who lives on the Isle of Man, was recently the recipient of one of the island's prestigious farming awards. Very generously, Anna donated her prize money to LAM Action! Here's her story which all our readers will find very inspiring.

Just days after Christmas 2020, after a few months of tests for shortness of breath, I was diagnosed with LAM. I was super fit, shepherd to 2 flocks of mountain ewes and had recently completed Wainwrights 200-mile Coast to Coast walk. I was a keen traveller, my biggest adventure being a camping and horse-riding trip to Mongolia. Within weeks my whole life changed.

In May '21 I had my 1st pneumothorax, and several more in the months following. 4 weeks in Nobles Hospital, Isle of Man and 8 weeks in Liverpool Heart and Chest. A tough time with no visitors due to Covid but the nurses were incredibly kind. A week before Christmas 2021 I returned home to the farm following bilateral talc pleurodesis.

2022 was a year of big change. I was now on oxygen 24/7 but determined to keep farming. With the help of Rachel

Moore this has been possible. Rachel helps 3 days a week on the farm.

As even walking short distances is difficult the mountain sheep had to be sold and the tenancies given up. I was, and remain, very sad about that. I was very proud of my Swaledale flock.

I've found traveling with oxygen incredibly hard. It's not possible to get to the LAM clinic at Nottingham without a 2-night stay. To arrange oxygen for this took almost 30 emails and phone calls over the period of a month. So, my spontaneous and far-flung travels have come to an end and my world has become much smaller. I'm also far less sociable than I used to be, I'm just too tired to speak after 7pm!

But there are positives! I've had to slow down. Cutting back to a lowland flock of 650 breeding ewes means I've got more time to ride my spectacular pony Amy, who has accepted the hissing and beeping of my oxygen concentrator incredibly well. I struggle to even climb a flight of stairs but on Amy I can 'walk' for miles.



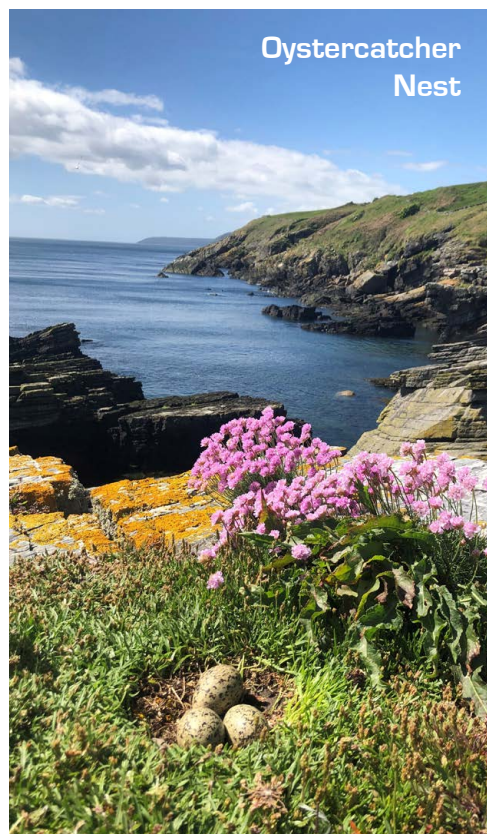
I'm fortunate that as we've always had quad bikes on the farm, I still have the mobility/ability to spend a lot of time outdoors. I'm only able to walk a few hundred metres without a rest but I do miles on the quad every day checking on the ewes. I carry an oxygen cylinder in a backpack and a spare in a basket on the quad.

After such long hospital stays I've come to appreciate what's around me. I stop and watch birds, learn the names of wildflowers and try to engage with the public through social media to promote farming (@manxshepherdess Insta and Twitter). I also love doing a fortnightly Farmertime zoom call with Year 3's, giving them updates through the farming year. Their questions are fantastic!

In August 2023 I entered the Farm Wildlife Advisory Group conservation challenge and in October won the overall Chough Award for Excellence in Conservation within Commercial Agriculture. The judges said we ticked all the boxes - public engagement, rare anthills, birds such as Chough and Curlew, orchids, grasses managed for wildflowers, targeted and careful use of wormers.

I donated the £500 prize money to LAM Action as I'm so conscious that we need research to find a cure. Having to use oxygen has been a major battle for me. I hope in the future, with further research, LAM can at least be detected and managed earlier and perhaps even cured.

Anna Kerruish



Under the Microscope: Professor Simon Johnson

As most of our readers know, Professor Simon Johnson started and runs the National Centre for LAM in Nottingham, has been a devoted trustee of LAM Action since our inception and is one of the world's foremost LAM researchers. Amongst other roles, Simon is Professor of Respiratory Medicine, University of Nottingham; Head of Division of Respiratory Medicine, Faculty of Medicine & Health Sciences; a member of the LAM Foundation scientific board; and a member of the specialist advisory panel for the Tuberous Sclerosis Association. Although we would be hard-pressed to find anyone from the UK LAM community who hasn't heard of Simon, you might learn a few things from our recent Q&A with him.



Why did you decide on a medical career?

I was always going to be a scientist of some sort and only went into medicine when I started working with patients in my first proper job as a lung function technician. I literally woke up one day with the idea to train in medicine so I could apply science to people. I did some extra A levels so I could get into medical school at UCL and didn't really look back.

Some of us know that you initially worked with Prof Anne Tattersfield in relation to asthma and switched to LAM when the asthma study didn't go as planned. Can you tell us about your career journey before you met Anne?

As I had a background as a lung function technician it made sense to train in respiratory medicine, so did general training in London and applied for the first respiratory training post that came out which happened to be in Nottingham. Having asked around, people said Nottingham was a good place to study respiratory medicine (mostly thanks to Anne's leadership), so Jan and I moved here with the intention of going back to London in 2 years. That was in 1993...

We were delighted that you participated in Ride London 2023 for LAM Action. How did you train for that 100 mile cycle (and how did you find the time!)?

I ride a bike anyway but definitely needed to train. I did the 12 week plan from the Ride London website. My daughter Naomi, her partner Oscar and their friend Alex also rode for LAM Action so we compared notes and went on a long training ride together a few weeks before the big day, I didn't really know if I had done enough before the day. Naomi and I rode together, the sun shone and we got round in under 6 hours, so we had a great day and raised some money for LAM Action.

Which do you have more of — bicycles or guitars?

I was equal on 4 of each until someone stole our mountain bikes. I still need to even the balance with another bicycle.

Any dreams of performing on stage?

I don't think other people hearing my guitar playing is really in the public interest, so doubt that will ever happen.

Those of us who have been around for a long time know that you are married to Jan Johnson, who retired as LAM Action's coordinator several years ago and currently helps with LAM research. How do you "switch off" from LAM and not bring it home with you?

We do talk about LAM and research a reasonable amount but not as much now as when Jan was working for LAM Action when there were always things to discuss. Now it is mostly Jan's research, she has contributed to five research papers

since leaving LAM Action and is currently working on two more. We do go cycling and work on our allotment together also. She is a good singer but refuses to sing along to my guitar playing, I have no idea why she hasn't taken up this offer.

Due to your efforts, the National Centre for LAM opened in 2011 and has treated over 400 women in the UK with LAM. Are there particular challenges in running the Centre?

The LAM Centre is funded by Highly Specialised Commissioning for the NHS. Once I had secured the funding in 2011 things got easier. The commissioning arrangements are different from most of the NHS and Highly Specialised team are very helpful and supportive. We can fund Wendy who makes sure everything is runs smoothly and everyone's tests are scheduled. We fund Hollie and Shannon our nurses who spend a lot of time talking to patients and delivering care. I am pleased to say that we have recently recruited some new doctors to add to the service. Professor Dominick Shaw, Dr Gauri Saini Dr SyGiin Chong are all experienced physicians and bring new skills to the service so the LAM Centre is becoming larger and should be able to deliver care long term.

What do you see in the future for women with LAM?

I am quite optimistic about the future; the whole field has made some big improvements in care already and there are some really strong researchers in the field. I am hoping we can develop drugs to completely stop disease progression in the not too distant future. Developments in stem cells and tissue regeneration will get to LAM one day, meaning we may be able to repair damaged lung tissue probably within the next ten to fifteen years. In the meantime we are getting better at targeting treatments earlier and working on drugs to improve the effect of mTOR inhibitors like rapamycin.

Thank you for taking the time to take part in the Q&A Simon, and thanks also to Kelly Vance for conducting the interview!

The next edition of LAMPost will be out in Spring 2024 with a deadline for submissions of **April 5th** - thank you!

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