



**Supporting women living with lymphangioleiomyomatosis**

**The latest news and updates on:**

**Raising awareness of LAM | Supporting those living with LAM | Building connections | LAM research outcomes | Having a bit of fun!**

## **May 2023 Newsletter Issue 2**

***In this issue:*** President and Vice President Reports | World Wide LAM Awareness Month | TSC Connect Day Saturday 3 June, Melbourne |

### **LAM Australia President's Report: Louise Lloyd**



Hello everyone,

I would like to thank everyone who donated during February for Research into a cure for LAM. We raised just over \$1,500 which will be used towards a stipend for an early career researcher working on LAM. Applications for a scholarship co-jointly funded with the Lung Foundation and The Thoracic Society of Australia and New Zealand will be released in June to celebrate World Wide LAM Awareness month.

The Rare Disease Day Morning Tea held on Feb 28 to meet the researchers at UTS that are working on rare diseases including LAM was a great success. This is a photo of the researchers working on LAM, Penny McKee (LAM Committee member) and Dr Allan Glanville who has been the Head of Lung Transplants at St Vincent's and now Macquarie hospitals in Sydney for over 30 years.



Some exciting research has been done at UTS on LAM and we will bring you an update at our AGM in June.

The AGM this year will be held on Sunday June 25<sup>th</sup> 2023, commencing at 4:30pm. Please save the date and come along – meeting link: <https://zoom.uts.edu.au/j/88273704738> We shall start the meeting with an update from the researchers at UTS and then hold our Annual General Meeting. At the meeting our committee members will stand down and a vote to fill the committee vacancies for Vice President, Treasurer, Secretary plus 4 committee members will be held. Can I encourage you to think about nominating to join the committee and if you would like to know how please contact me at [president@livingwithlam.org](mailto:president@livingwithlam.org)



Worldwide LAM Awareness Month kicks off in June. In Australia we will have T-shirts available (store link will be sent out shortly) for you to buy for yourselves, your family and friends. We are setting up a worldwide competition with a group of other support groups from around the world for the best photo of a LAM T-shirt in front of an iconic building or world heritage site. The prize for the best photo in Australia will be \$500 towards a weekend away and/or dinner of your choice – get your cameras ready. In Sydney we are holding a lunch at the Opera Bar (with photos of the Opera House and Harbour Bridge) for members, family and friends on Saturday 10 June. It would be great to see you there!

*Louise Lloyd* [president@livingwithlam.org](mailto:president@livingwithlam.org)



## LAM Australia VP President's Report: Corrine Tye-Lim

Dear All,

As the weather gets cooler, there are great options to stay active if you can't go outdoors. Exercise at home through free fitness apps and find activities you enjoy: <https://www.boomfit.com/en/blog/best-fitness-apps-b22.html>

The next Bridge to Brisbane (B2B) date if people want to join my Living with LAM pink walkers team in person or virtually will be on Sunday 15<sup>th</sup> October 2023 my birthday this year. I will send out information links once available. Your support in any way is always appreciated.

This month I had the opportunity to take two holiday breaks, a visit to see family in WA. Another to Hervey Bay and K'gari Island with my husband. The second one was relaxing, immersed in nature. Time to pause, switch off and take a deep breath from the usual hustle and bustle of life! A reminder to make time to relax & enjoy whenever you can. Here are some photos from K'gari & Hervey Bay (travel photography, a little hobby).



Leading up to June our Worldwide Awareness Month, please reach out if you are able to host an event with LAM friends in your local area, State or Territory. I will be organising one in Brisbane. With warm wishes, Corrine xx E: [social@livingwithlam.org](mailto:social@livingwithlam.org)



***\*\*\*A special thank you to Jeff and Heather Telford for our updates on COVID vaccinations and boosters!***

### ***DO I REALLY NEED A COVID BOOSTER SHOT?***

A course of COVID-19 vaccinations or a COVID infection will give you some protection against future infections. Unfortunately, your immunity begins to wane within a few months of your last dose particularly against new strains of the virus due to falling levels of antibodies in your blood.

Adults with a medical condition such as LAM or anyone over 65 are advised to have a booster six months after their last vaccination or last infection.

The bivalent vaccines are preferred since they give greater protection against newer strains of the virus.

### ***CAN'T I RELY ON ANTIVIRAL DRUGS INSTEAD OF HAVING A BOOSTER?***

Antiviral medications, such as 'Paxlovid' or 'Lagevrio' don't kill or eradicate viruses from your body in the way that antibiotics kill bacteria. They block enzymes which your body's own cells use to manufacture more viruses. This will buy time and give your immune system a chance to catch up and make antibodies against the virus.

Paxlovid is the best antiviral medication for most people but it can't be used if you're also taking certain antibiotics, heart medications or cholesterol lowering drugs. The five day course of Paxlovid should start as soon as possible after a positive RAT or PCR result. If you're taking Sirolimus or Everolimus for LAM your doctor will recommend you withhold the medication while taking your five day course of Paxlovid, and up to five days afterwards.

After completing their course of Paxlovid some people find their symptoms return a few days later and the RAT which had become negative is now positive again. This "COVID rebound" is usually less severe than the initial infection and is treated symptomatically with Paracetamol or Ibuprofen. A second course of Paxlovid is usually not recommended.

### ***TAKE HOME MESSAGES***

1. Keep up-to-date with your COVID vaccinations. If it is 6 months or more since your last shot or COVID infection, get a bivalent booster.
2. Early diagnosis of COVID infection is important. RATs often don't detect COVID infection in the early stages so repeat the test every twelve to twenty four hours if you are unwell.
3. Early treatment with antiviral medication reduces your viral load and may assist your immune system in stopping severe infection. Contact your GP or Respiratory Physician as soon as possible to discuss taking Paxlovid or Lagevrio.
4. While you are sick, check your temperature and respiration rate, monitor your oxygen saturation at home using a pulse oximeter, and if you're getting worse contact your doctor immediately.

**SAVE THE DATE:**



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## TSA/ Living with LAM Saturday 3 June 10-5pm Library at the Dock, 107 Victoria Harbour Promenade, Docklands.

Join us for an event for adults living with TSC, companions and carers of adults living with TSC, and adults living with LAM.

It's easy to register:

<https://tsa.org.au/community-connect/>

## Community Connect, Melbourne 2023

This event is proudly co-hosted by



**Cost: Bookings are essential.**

The registration fee (of \$50) has been subsidised by Living with LAM for those wishing to attend.



## The Back Page

**Share your member story with us! Send text (250-400 words) and pics to Penny at [thevowfactor@gmail.com](mailto:thevowfactor@gmail.com).** Even if you don't have a written story to tell, your pictures (with a bit of background information, e.g who and what!) can provide a glimpse of life with LAM and give hope to others.

**About your LAM newsletter:** We are going through a newsletter 'renovation' in an effort to streamline and make our content relevant to LAM members and their families.

A recent request on our Facebook page for members to post what they'd like to see in future newsletters included requests for information on:

- *Holistic health*
- *Low intensity exercise*
- *Healthy eating*
- *Nutrient dense foods*
- *Recommended meditation apps and where to find them*

Hello everyone,

As I'm (again belatedly) formatting the newsletter I thought I'd add an item that speaks to the above: **nutrient dense food**. After putting a pause on being accepted for LTXP listing last October I decided to explore further adjustments I could make to improve my general SOB which had been impeding my mobility for some time. I set a goal to lose 10kg and made a few adjustments to my diet: **protein packed, no alcohol, no sugar, as much fruit and vegetables** as I like, generally smaller servings and a bit of a brain retrain to stop thinking about food. **Carbs (preferably unprocessed)** stayed on the list.

The resulting weight loss (8.9kgs to date. Clearly there's no rush!) has made a huge difference to my SOB, energy and general quality of life. Weight loss is not a cure and my numbers on paper still paint an advanced LAM profile, but it has made me feel the best I have in about 4 years. **Regular exercise and rest** have remained essential tools in this journey.

**Penny McKee**, Committee Member

**LAM Noticeboard: Offer of a free POC & oxygen concentrator (no longer required) from a LAM family member based in Sydney. Each item just needs a service. Please contact Louise Lloyd ([louise.lloyd@livingwithlam.org](mailto:louise.lloyd@livingwithlam.org)) if you are interested in accepting this kind offer.**





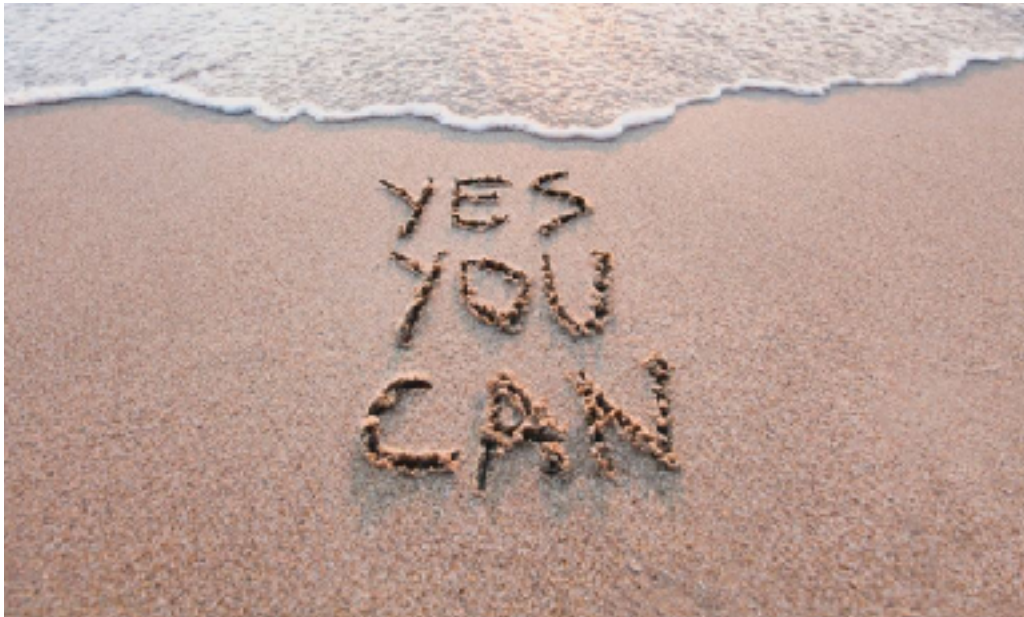
## New to the LAM community?

Become a member: <https://www.livingwithlam.org/join-us/>

Join our FaceBook page: [Living with LAM Australia](#)

**Useful Links:** [IPTAAS](#): Isolated Patients Travel and Accommodation Scheme (NSW). If you live outside Sydney and you need to travel for medical appointments, IPTAAS can assist with travel and accommodation expenses. It is easy to apply and payments are prompt.

### Quote of the Month:



### Your friendly Living with LAM Committee:

**President:** Louise Lloyd

**Vice President:** Corrine Tye-Lim

**Secretary:** Alison McIvor

**Treasurer:** Lauren Sharpe

**Committee:** Penny McKee | Leanne Smith | Kate Wingrave |

**Living with Lam acknowledges the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to their cultures, and to elders both past, present and emerging.**