



## Supporting women living with lymphangioleiomyomatosis (LAM)

The latest news and updates on:  
Raising awareness of LAM | Supporting those living with LAM | Building  
connections | LAM research outcomes | A bit of fun!

Living with LAM

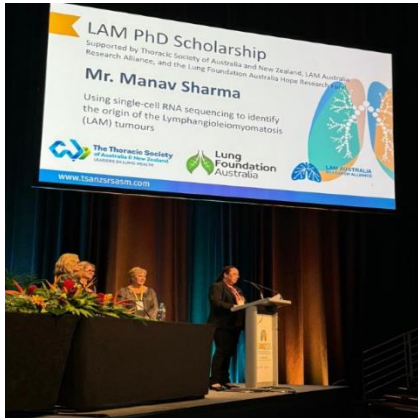
### April Newsletter 2024



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

It's been a very busy start to the year, I hope you are all keeping healthy and now enjoying the break from the humidity.

As you aware, last year we established a jointly funded PhD Scholarship with the Lung Foundation Australia and the Thoracic Society of Australia and New Zealand. Just recently I attended the Thoracic Society Conference where I had the pleasure of awarding the joint scholarship to a promising young PhD student who will spend the next 3 years focused on researching LAM. I was also given the opportunity to address the conference delegates, all respiratory researchers, scientists, clinicians, and professionals, shedding light on LAM and the associated challenges we face. On the following night I had the pleasure of attending the Lung Foundation Gala dinner where I was once again invited to talk about LAM. Raising the awareness of LAM among researchers and medical professionals is a crucial step towards early identification of LAM in patients and exploring the underlying causes, which in turn may lead to the development of effective treatment options or improved quality of life for those of us living with LAM.



As we approach the end of the financial year, I would like to remind you that your membership is due (\$25 for existing members) and to book in the date of our **Annual General Meeting (AGM)**, please save the date: **Sunday 23<sup>rd</sup> June 2024 at 4:00pm (AEST)**. We have vacant positions coming up on the Committee such as the role of the President, Vice-President and Treasurer, If you are interested in nominating yourself or someone else for these positions or any other roles on the committee please reach out to me at [louise.lloyd@livingwithlam.org](mailto:louise.lloyd@livingwithlam.org).

It is very important that we fill these positions to ensure the continued success of our Association and to support the advancement of our medical breakthroughs in the future. Your participation and involvement are greatly appreciated. I look forward to hearing from you.

All the best, Louise x



### Corrine Tye-Lim: Vice President's Report

Brisbane LAM friends had a wonderful lunch catch up on Saturday 9th March 2024 at the Kedron-Wavell and we welcomed Suzanne to our community. Our next luncheon will be on Saturday 8<sup>th</sup> June to celebrate Roxy's milestone birthday, please save the date.



These past few months I have heard from newly diagnosed and interstate LAM friends who are travelling to Brisbane. Please know you are always supported, and we will try to meet up in person with you if in Brisbane, lend an ear / help answer queries.

As we head towards Autumn it's a nice time of year to get outside in the fresh air and enjoy some activities or exercise. Please save the date for the **2024 Bridge to Brisbane**. I will share a link to the team and fundraising pages in the next newsletter.



You are welcome to join us walking at the event or virtually! Please contact me for more information E: [social@livingwithlam.org](mailto:social@livingwithlam.org)

With best wishes, Corrine



## Tuberous Sclerosis Australia (TSC) Connect event

I was thrilled to be asked by Jacqui Gambrell of TSC Australia to present at the annual TS Connect Conference where those newly diagnosed or living with TSC come together to connect and share stories.

Our own Alison McIvor had previously spoken at a TS Connect conference in Melbourne last year. TS Connect 2024 was held in Sydney at UNSW on 23 March. I was aware that some in the TS Connect audience were either parents of newly diagnosed children with TSC or that they were seeking awareness of how LAM may progress if their child was also later diagnosed with LAM. With this in mind, the talk I gave outlined my path of TSC symptoms and diagnosis in the early 80's to the wobbly path of a LAM diagnosis some 30 years later.

The talk made reference to tips to make living with TSC-LAM easier (such as using a disabled parking sticker, accessing [IPTAS](#) and connecting with Living with LAM) and references the value of making adjustments, acceptance and accepting help as and if your symptoms change. **Penny McKee**



**TSC Community Connect, March 2024 Sydney**



## **A little about our Living with LAM Committee member Penny McKee:**

Penny McKee is married with two beautiful daughters. She is a content and copy writer and lives in picturesque Port Macquarie on the NSW north coast. Here, she shares a little of her TSC-LAM (Tuberous Sclerosis Complex – Lymphangiomyomatosis) journey with us.

Penny's journey began with a diagnosis of TSC (Tuberous Sclerosis Complex) at the age of almost 13, after experiencing various episodes such as fainting spells, absence seizures, and unusual behavior. Despite taking medication for TSC, life continued normally until the diagnosis of LAM (Lymphangiomyomatosis) during her second pregnancy, causing shortness of breath. Initially misdiagnosed, proper medical attention led to the correct diagnosis and treatment plan.

Penny highlights the challenges of managing LAM, including regular visits to specialists in Sydney from rural NSW and coping with the progression of the disease, such as a collapsed lung in 2015. Although her lung function has declined and the possibility of a lung transplant looms, she has learnt to live with it by adjusting. 'I pay attention to my diet, sleep and exercise. I applied for a disabled parking sticker, and I use it'. Despite these challenges, Penny remains grateful for the support of family, workplace accommodations, and advancements in medical care.

Reflecting on the journey, she emphasizes the importance of self-care, acceptance, and gratitude in navigating life with chronic conditions. Despite the occasional struggles, Penny remains resilient and fully engaged in life, appreciating the support systems and medical resources available.



## **The Back Page**

New to the LAM community?

Contact us: [enquiry@livingwithlam.org](mailto:enquiry@livingwithlam.org)

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

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

LAM FAQ's: What questions did you have upon diagnosis? What questions do you have post diagnosis?

### **Useful Links**

[www.livingwithlam.org](http://www.livingwithlam.org) our website has many useful factsheets and links for information and support for those living with LAM, their families and friends.

<https://www.thelamfoundation.org/> The LAM Foundation website has very useful factsheets and information relating to LAM.

[IPTAAS:](#) Isolated Patients Travel and Accommodation Scheme (NSW)

### **Remember to:**





**Your Living With LAM Committee:**

**President:** Louise Lloyd

**Vice President:** Corrine Tye-Lim

**Secretary:** Alison McIvor

**Treasurer:** Alvin Lim

**Committee:** Penny McKee & Leanne Smith

**Dates for your Diary**

- Saturday 8 June: LWL Brisbane Lunch (& Roxy's 50<sup>th</sup>!)
- Sunday 23 June 4pm (AEST) Living with LAM AGM
- EOFY: Living with LAM \$25 membership due
- Sunday 8 September: Bridge to Brisbane

**The Living with LAM Committee welcomes your nomination!**

To keep the great work of the Living with LAM Committee afloat consider nominating yourself or someone else to a position on the Living with LAM Committee. Contact Louise with your nomination:

[louise.lloyd@livingwithlam.org](mailto:louise.lloyd@livingwithlam.org).