



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

November Newsletter 2023



LAM Australia President's Report: Louise Lloyd

We need your help!

The researchers working on finding a cure/better health outcomes for ladies with LAM, at the University of Technology Sydney (UTS) are seeking seed funding of \$10,000 -15,000 for a project:

Early diagnosis, as with many chronic diseases, is key to maintaining the quality of life and patient survival. Single-cell sequencing (sc-Seq) has changed the face of biology by allowing researchers to investigate samples at a single-cell resolution. LAM cells can be found in the blood of LAM patients even during the early stages of the disease, indicating that the blood could provide a strong biomarker for LAM diagnosis.

This work is incredibly important for diagnosing and providing information that will help those living with LAM with a cure or better health outcomes in the short and long term. Reducing this time will allow for appropriate interventions to commence earlier and avoid unnecessary treatments due to misdiagnosis. This fund will take important steps forward in improving the health of women with this rare disease and provide an important understanding of its origins and development. Using the current advanced sequencing technologies, we have an opportunity to understand this disease in a way



that could not be done 5-10 years ago. The identification of LAM cells will greatly improve screening and may help to explain variations in treatment response to Sirolimus, helping inform treating physician's treatment regimen decisions.

If you can help us with raising funds to support the researchers with this important work, please use this link to donate towards the fund: <https://www.livingwithlam.org/donate/>

The **Bridge to Brisbane** fun run....well done ladies - **over \$3,800 raised**....we had great representation with both Corrine and Roxy and their teams wearing our T-shirts, promoting LAM awareness. Penny (wearing her LAM T-shirt), also organised an early morning fun walk in Port Macquarie – a beautiful early morning start to the day. Thank you to our amazing ladies and all that donated to support them, it is much appreciated.

You may have come across an announcement that Pfizer in the U.S. will no longer sell Rapamune (Sirolimus) in the U.S. however Rapamune will continue to be available outside the U.S.

Don't forget to send in your photos wearing your LAM T-shirts (at a place of interest) for the \$500 prize which will be announced at the AGM in June next year.

As we come up to the end of the year, I would like to wish you all a very happy Christmas and New Year and hope that you are all spoilt by Santa



All the best, Louise Lloyd

president@livingwithlam.org

Corrine Tye-Lim: Vice President's Report

Hi Everyone, Overall a fantastic day completing 4.5km in 32 degrees heat with my team for **Bridge to Brisbane** on my birthday this year on Sunday 15th October. It was really hot, but we enjoyed chatting and walking the whole race and drinking water at each station. I love how there is entertainment for everyone during this race including Opera stage performance in the Inner City Bypass Tunnel and DJ booths at bus stops along the way! Thank you to all my sponsors and donors so pleased to have raised personally **\$1467 this year for LAM research**. Don't worry I did rehydrate after the race with cold



cocktails, birthday cake, live guitars jam and singing.



Corrine Tye-Lim

Corrine Tye-Lim

Share my page



Download poster

RAISED SO FAR

\$1,467

MY GOAL

\$1,200





Corrine and her Bridge to Brisbane LAM Fundraising at the finish line, October 2023

From Roxy Papatheoharous:

On the 10th anniversary of my diagnosis with LAM, I was grateful to be able to partake in the Bridge to Brisbane to help raise awareness of LAM and to help raise much needed funds that can be contributed towards research for a cure. Ten years ago, I wasn't sure if I would be here today, and I am so grateful to my family and friends who have provided their support and generous donations for this fundraiser. I'm also grateful to my partner David who encouraged me and walked by my side in the searing Brisbane heat on the day! I was able to raise \$1075 in donations for the LAM Australia Research Alliance and had some very informative conversations with other racegoers who were curious about LAM, after noticing the shirts we were wearing. Big thanks to Corrine for organising the team and I look forward to participating again next year!



Brisbane Lunch

Brisbane End of Year Lunch held Saturday 28th October 2023 at South Bank Parklands with the LAM ladies in attendance:

Bottom to Top Left: Lesley, Tamar, Corrine, Jenny, Roxy (welcoming her back to QLD from SA), Gai, Rose & Diane (Jen's mum). It was wonderful to catch up sharing stories and what's been happening since last year with the back drop of the beer gardens in Southbank Parklands and cool weather with a bit of sunshine. Roxy shared her mum's amazing Christmas Craft gifts where all proceeds go to Living with LAM. I look forward to organising another one in the new Year.



With warm wishes, Corrine xx E: social@livingwithlam.org

Penny McKee: Committee Member, Circle Work for LAM 6.30 am Friday 13 October 2023

Having not engaged in LAM fundraising for some time and inspired by Corrine, I organised a simple fundraising event which yielded about \$1100 for LAM research and awareness.

Port Macquarie put on a stunning sunset for a small gathering of friends who lapped the local Oxley oval with me. Apart from fundraising, colleagues across my large govt department were made aware of LAM through an internal newsletter article. One colleague commented that a friend of hers was looking into her mother's own unexplained SOB.

Why a lap around an oval? A few reasons! 1. For LAM ladies, completing a simple walk around an oval can be challenging. 2. An oval shape represents unity and 3: 'Circle work' is a nod to those of us from the country who may have grown up around people doing 'circle work' in cars to get attention!

And why sunrise? New beginnings, of course! And a morning coffee afterwards goes down a treat.



Penny (note that LAM shirt!) prior to sunrise walk to raise LAM funds.



Post sunrise walk and coffee bound! Oxley Oval, Port Macquarie, October 2023.

Your LWL Newsletter: It's late. Again! My apologies. Full time work, study and parenting while husband is away working has had a big impact on available time. Ugh. If you'd like to help out next year with the newsletter please drop me a line on Facebook. Send us your short story with a photo and we'll pop it in the next newsletter.

Have a great Xmas and we'll see you in the new year! Penny McKee



Introducing our Living with LAM Committee member Leanne Smith:

Hi my name is Leanne Smith, I am 52 years old and live in Grafton NSW. I work full time in the Foster Carer Recruitment and Development team for an NGO. I am the happily divorced mother of 2 grown children. I was diagnosed with LAM in January 2008 and I am looked after by the wonderful team led by Professor Peter Hopkins at the Prince Charles Hospital Brisbane QLD. Living across the border has its challenges as does living rurally with any illness, but we all somehow manage it okay. I have had a few ups and downs with LAM along the way but mostly I seem to travel along okay, I sit around the 35% lung function and take 0.5mg of Sirolimus, I try to not look or dwell on what I can't do, rather embrace and enjoy what I can do. If you are ever in Grafton or travelling through, give me a call, would love to catch up. 😊



2023 LAM Committee Member Leanne Smith



The Back Page

[New to the LAM community?](#)

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

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

www.livingwithlam.org our website has many useful factsheets and links for information and support for those living with LAM, their families and friends.

Quote of the Month





Your 2023 Living With LAM Committee:

President: Louise Lloyd

Vice President: Corrine Tye-Lim

Secretary: Alison McIvor

Treasurer: Alvin Lim

Committee: Penny McKee | Leanne Smith