



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!

July 2023 Newsletter Issue 2

In this issue: President and Vice President Reports | Vice President's Report | Jenny's story

LAM Australia President's Report: Louise Lloyd



Hello everyone,

We held our **Annual General Meeting** on 25 June (see website for details), thank you to our Researchers Alen Faiz and Bernadette Saunders for taking the time on their Sunday to do a presentation update on the very exciting LAM research currently being worked on at UTS. Thank you also to our outgoing Treasurer Lauren Sharpe and our committee members - Pat Evans and Kate Wingrave and we welcome our new Treasurer - Alvin Lim. Our committee members currently are:

Louise Lloyd – President

Corrine Tye-Lim – Vice President

Alison McIvor - Secretary

Alvin Lim – Treasurer

Penny McKee – Committee member

Leanne Smith – Committee member

I would personally like to thank the office bearers and committee members - as a volunteer association we rely very heavily on these people for their time and support, with having LAM, working full time and for some, raising a family, it is a big ask and everyone has contributed and supported and worked to provide information, support, fund raising events and advice to new and existing members – I appreciate their help and look forward to working with them again this year.

My term as President will become vacant in June next year at our next AGM, I will not be standing for re-election as President but would like to spend this year mentoring and coaching our next President, so if



you would like to nominate, please let me know (email: louise.lloyd@livingwithlam.org) and we shall work together to effect a smooth transition.

I would like to also thank our donors – without you we wouldn't be able to support our ladies living with LAM, their family and friends or support our researchers in finding better health outcomes for those with this rare disease. You will be very pleased to know that through your contributions we have signed off on a **joint-funded research project** with The Lung Foundation and The Thoracic Society (launch date will be announced shortly). This project will support an early career researcher to work on LAM for the next 3 years!! Thank you for helping to make this happen, it has taken 2 years with many meetings, iterations of the agreement etc..so very exciting to now have the project signed off – our challenge now is to raise funds to keep the project going in future years and support upcoming researchers working on LAM.

A gentle reminder that your **membership fee** is now due, please see website for details or contact secretary@livingwithlam.org (\$35 for new members and \$25 for renewal). Our members provide peer support for new and existing members and help to raise funds for research to find a cure for LAM. We have members providing much needed advice and medial updates, and help us with events and promotions – thank you, you are very much appreciated!

Worldwide LAM Awareness Month in June saw multiple events happening, a lunch in Brisbane and one in Sydney. Thank you to all who attended and bought our Tshirts for photos to go into the \$500 prize which will be awarded at the AGM next June. Remember to post your photos wearing our Tshirt (purchase at: [Products | Living with LAM](#)) at an iconic site or beautiful spot or event – watch for them at the Bridge to Brisbane run in October!



Louise Lloyd president@livingwithlam.org



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

Hi Everyone,

This year I will be participating again in Bridge to Brisbane with a team to walk/run for a cause that is very close to our lungs. I have been training since the start of July for the 4.5km and enjoying the extra exercise for winter.

Living with LAM are doing amazing work with research projects underway to find better diagnostic techniques, tailored treatments and one day hopefully a cure for this rare lung disease (Lymphangioleiomyomatosis). We are raising awareness by wearing t-shirts at the race (purchase at: [Products | Living with LAM](#)). Any support to help my fundraising goal or leaving a message for my team to read for the event is much appreciated. Thank you to those who have kindly donated. <https://bridgetobrisbane.gofundraise.com.au/page/CorrineTye-Lim>

If you would like to join the Bridge to Brisbane this year Virtually (you can time your walk/run anytime between Friday 13th October to Sunday 22nd October 2023), please read the info here: <https://bridgetobrisbane.com.au/virtual-race-2023/>

If you would like to join the Bridge to Brisbane this year in person, here are the steps to register in my team and select my charity. If you have any queries please email me: social@livingwithlam.org

1. <https://enterb2b.com.au/enternow.aspx> Select Join a Team entry to register.

Join a Team

Use this option to join an existing team.

You'll need the team name and, if your Team Manager is paying for you, the access code for your team.

Join a Team

2. Team Entry Details: search for Living with LAM Fam & Friends (no PIN required) Starting Zone: Pink Walker



SundayMail Transurban BRIDGE TO BRISBANE

TEAM ENTRY DETAILS ● = These questions require a response.

Please untick if you are NOT joining a team. ☒

Type to search for your team name: ● ✔

Team PIN (Only required if your Team Manager has supplied one)

STARTING ZONE

Starting Zone ●

PERSONAL INFORMATION


Postal Address ●

3. Fundraise - select LAM Australia Research Alliance then proceed with selected charity:

Fundraise for a charity that's close to your heart

Choose your charity by either selecting from our preferred charities or searching thousands of other causes.

If your charity doesn't appear when searching, you can nominate them below.



LAM Australia Research Alliance

4. Payment Page should have your name, in Living with LAM Fam & Friends team, Fundraising for: LAM Australia Research Alliance and your B2B t-shirt size. *Note my team will wear the Living with LAM tees on the day (available here: <https://www.livingwithlam.org/shop/>)

SundayMail Transurban BRIDGE TO BRISBANE

Entry details for: Corrine Tye-Lim		Review/Change	Delete this entry
Item	Cost	Qty	Disc
Bridge to Brisbane 4.5km - Flash Sale Discount Applied			
Bridge to Brisbane T-Shirt - M		1	
Total for: Corrine Tye-Lim , in Living with LAM Fam & Friends			\$45.00
Fundraising for: LAM Australia Research Alliance			

Entry details for: Alvin Lim		Review/Change	Delete this entry
Item	Cost	Qty	Disc
Bridge to Brisbane 4.5km - Flash Sale Discount Applied			
Bridge to Brisbane T-Shirt - XXL		1	
Total for: Alvin Lim , in Living with LAM Fam & Friends			\$45.00
Fundraising for: LAM Australia Research Alliance			

Total for this order \$90.00

☐ Empty Cart



JENNY'S STORY

I met a lovely man today, his name is Matt. Matt shared the story of his Mum Jenny with me.

Living in Rockhampton QLD in the 70's, Jenny together with her husband Norm were newly married but for some unknown reason struggled to get pregnant and sought various medical advice before being told that they would not be able to fall pregnant. So they started the long process of adoption and in 1975 adopted their first child, a little girl named Jacqueline. Adoption was tricky so Jenny & Norm were resigned to the probability of not having any more children. However, Jenny fell pregnant in 1977 and during pregnancy experienced lung collapse followed by a pleurodesis (sound familiar) where a biopsy was taken during the birth and sent to Brisbane, Canberra and Heathrow Hospital in the UK – the original diagnosis out of Brisbane and Canberra was that she was suffering a form of cancer. However, the pathologists in Rockhampton did not agree with the diagnosis and awaited the results from Heathrow that she in fact had LAM equally devastating to hear but perplexing and frustrating in that little was known or information available about the disease.

The family then moved to Brisbane in 1988 to be closer to medical support where Jenny went on the waiting list for a lung transplant awaiting 3 long years where it was looked likely that she would not survive the waiting period. Until an 'almost' match became available in 1991 when she had a lung transplant (single) which was performed by Dr Victor Chang at St Vincent's hospital in Sydney and from then she was managed by Dr Allan Glanville in the first 18 months and then Dr Hickey for the next 13 years, Jenny passed away 6 weeks before her first grandchild was born. Yes...she was obviously a tough cookie and managed to raise her children (with in no small part supported by her husband, friends and family) whilst managing the ongoing symptoms of LAM and the side effects of the anti-rejection drugs used at that time.

Matt remembers the debilitating side effects of the drugs and the impact they had on his mother's health as well as how this impacted on his family, himself and his sister's young life. They learnt very quickly to be independent, resilient and responsible and hope that sharing Jenny's story will raise further awareness of the diseases as well as resonate with other family members of those with mothers, sisters, wives with the disease.

It was a pleasure to meet Matt, he is keen to become involved and do what he can to support us, so I have recruited him, his sister Jackie and friends for the upcoming Bridge to Brisbane run with Corrine – please look out for them (they will be wearing our TShirts) and say hello!

Louise



My Visit to the UK National Centre for Lymphangiomyomatosis

Nottingham may be famous for the stories of Robin Hood and Nottingham Castle, but it is also the home of the largest LAM research group in the United Kingdom, led by Professor Simon Johnson. Simon has worked in the field of LAM, both as a clinician and a researcher for over 20 years. In 2011 he led the establishment of the UK National Centre for Lymphangiomyomatosis, where he remains the director. In the last 10 years the centre has treated over 400 LAM patients. Recently, I was fortunate enough to visit with Simon and his group, at their laboratory in the Nottingham Biodiscovery Unit within the University of Nottingham. It was a fascinating day. I enjoyed hearing about the latest research into LAM from members of Simon's groups and describing some of our own work. The group shared some of their recent discoveries demonstrating the involvement of MAST cells in LAM progression, and discussed past clinical trials and ongoing studies that will hopefully progress to new therapies for LAM. We hope to be able to work collaboratively with Simon and his team in the future to progress research into new therapies and biomarkers for LAM.

Assoc. Prof. Bernadette Saunders (UTS LAM researcher)

Circle Work for LAM 6.30am Friday 13 October

Choose your local oval and take a morning stroll!

On the heels of and inspired by Corrine's Bridge to Brisbane LAM Fundraiser on Sunday 15th, **Circle Work for LAM** give you a chance to warm up!

It's easy to help. Join and/or sponsor me to raise LAM funds and awareness by taking a stroll around your local oval at 6.30am on Friday 13 October.

Penny McKee, Living with LAM Committee Member



Joint TSA and Living with LAM Community Connect Event

Source: TSA – Dr Helen Whitford and our LAM ladies at the event:



The joint Tuberous Sclerosis Australia (TSA) and Living with LAM – Community Connect Event – was held in Melbourne on Saturday 3 June 2023. This event was for adults living with Tuberous Sclerosis Complex (TSC) and Lymphangioleiomyomatosis (LAM) and their partners and carers. Attendees joined us from Melbourne and Victoria, as well as Queensland and Western Australia.

The first half of the day focused on kidney issues in TSC and kidney health, with an excellent presentation from Dr Matt Sypek – Nephrologist at Royal Melbourne Hospital. He discussed kidney screening, surveillance needs of those living with TSC and potential treatment options. Matt pointed out that whilst most people living with TSC have kidney AMLs, for the majority of people the AMLs won't cause any issues.

At lunchtime, a number of people from the Living with LAM Community joined the Community Connect Event for the second half of the day, which was LAM-focused. Alison Mclvor – who is both a Committee Member of Living with LAM and TSA, and has lived experience of both LAM and TSC – spoke about living with both conditions - including the impacts and what she does to try and minimise these.

A huge highlight was the presentation given by Dr Helen Whitford – Respiratory Physician at The Alfred Hospital in Melbourne – and the specialist that many of our Melbourne/Victorian community are patients of. She shared her expertise on LAM which encompassed the most recent research and options for treatment. Helen also covered a range of important related issues such as vaccinations, fertility and contraception. She also answered a number of questions from the audience who were highly engaged. Many of the Living with LAM attendees spoke about how nice it was to meet people in person again at the Community Connect Event – and not only hear from extremely knowledgeable medical experts, but share experience with others 'Living with LAM.'

Alison Mclvor – Secretary Living with LAM



TSA News: Funding of Abdominal MRI's for TSC Patients!

TSA are pleased to announce that Abdominal MRIs will now be funded for patients with TSC – under the Medical Benefits Scheme (MBS). In other words, they will be **free** for patients with TSC in Australia.

Rare Voices and two neurologists at The Royal Melbourne Hospital have assisted TSA with an advocacy campaign to make this happen. Read here for more details: [We did it! Abdominal MRIs will be funded for patients with TSC - Tuberous Sclerosis Australia \(tsa.org.au\)](https://www.tsa.org.au/news/we-did-it-abdominal-mris-will-be-funded-for-patients-with-tsc-tuberous-sclerosis-australia)

In short, it will make the surveillance of renal tumours much more manageable – particularly from a cost perspective.

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New to the LAM community?

Become a member: <https://www.livingwithlam.org/join-us/> Join our FaceBook page: [Living with LAM Australia](https://www.facebook.com/LivingwithLAMAustralia)

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.



The Back Page

Your friendly Living with LAM Committee:

President: Louise Lloyd

Vice President: Corrine Tye-Lim

Secretary: Alison McIvor

Treasurer: Alvin Lim

Committee: Penny McKee | Leanne Smith|

Share your member story with us! Send text (250-400 words) and pics to Penny at 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*

Quote of the Month:

"Become more
aware
of what's really
worth your
energy."

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.