Living with LAM
www.livingwithlam.org

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!

January 2023 Newsletter

In this issue: Rare Disease Day Feb 28 | UTS Rare Disease Day Morning Tea | Corrine's Recovery After Pleurodesis | A Guide to Making Bequests in Your Will | Brisbane LAM Ladies Lunch Feb 9 | Member Stories: A Template to Share your Story to Raise Awareness by Penny McKee

LAM Australia President's Report: Louise Lloyd

Hello everyone and a happy new year,

I do hope you all enjoyed the summer break – I did and am now trying to shed those extra kilos!

Our member database is now 'live' on our website for new members to register and for our existing member's to update their data. You shall all receive your link and email with instructions to update your record in the next couple of weeks. Thank you all for your patience and to those that performed the testing, it is a complex and tricky build that has taken some time but I am now confident that we can provide a secure repository for our member data.

Please be assured no data will be released from the database at any time without your prior approval. For existing members, as soon as you have saved your updates we will be sending you a special gift to the address we have listed on the database.

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Exciting news for **Rare Disease Day 2023** – the **University of Technology Sydney (UTS)** are hosting a morning tea on **28 February** to meet the researchers who are working on LAM and many other Rare Diseases:

UTS

Rare Disease Day: 28 February

Morning Tea with UTS Researchers

RARE DISEASE DAY®

It's our great pleasure to invite you to a special morning tea to recognise **Rare Disease Day 2023**.

Many diseases are so rare that few people are aware of the impact they have within our community.
On Rare Diseases Day 2023, UTS are holding a Morning Tea to 'Meet the Researchers' who are doing valuable work on the research of rare diseases.

The world-leading work being undertaken by researchers at UTS is something that we need to recognise and celebrate so we would like to bring together our researchers with those living with a rare disease, their family and friends, our students and staff, to showcase their research and to thank them for their efforts.

The rare diseases that will be showcased include:

- Lymphangioleiomyomatosis (LAM)
- Interstitial Pulmonary Fibrosis, silicosis, A1AT deficiency and cystic fibrosis
- MCT8
- Multiple Sclerosis
- Huntington's disease
- Motor neurone disease linked to algae toxin exposure
- Familial cancer syndromes
- Ovarian cancer
- Cowden syndrome and Multiple Endocrine Neoplasia Type 1 and 2
- Rare disease from the hereditary monogenic cardiomyopathy angle

This is an open invitation so please feel free to share this event with family and friends.
We look forward to seeing you there!

Tuesday 28 February 10am-12pm
RESHub, Building 2, Level 5
Broadway, Ultimo NSW

Please join us if you can – updates will be posted to you and will be posted on our social media about the event.

To further **celebrate** the research being done on LAM we will be setting aside all donations made during the month of **February to fund research**. We will soon be kicking off a joint funded early career researcher stipend in conjunction with The Lung Foundation and The Thoracic Society and hope our donations during February will support even more researchers becoming involved in finding a cure and/or better health outcomes for our LAM ladies. Please consider making a donation at: **https://www.livingwithlam.org/donate/**

Just recently my husband and I updated our wills and set aside a bequest to further research on LAM. I have attached the **wording** suggested by our lawyer at the end of the newsletter should you wish to include a bequest when **making or updating** your will.

I am really looking forward to meeting the **LAM ladies in Brisbane for lunch on 9th February,** it will be so good to meet and have a chat and a laugh in person. Hopefully this year will be easier to travel to meet as many ladies with LAM as I can, fingers crossed!

All the best - Louise Lloyd president@livingwithlam.org

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

Happy New Year! Wishing you all happiness, health, peace and laughter in 2023. For those of you celebrating the Lunar New Year of the Rabbit, Xīn Nián Kuài Lè 新年快乐!

I am pleased to report that my lung function test completed early January has shown good improvement since my previous one at the end of October 2022 & I am now back to 6-monthly check-ups. I have been asked to share **my recovery journey after pleurodesis:**

Date	Activities / Goals	Actions/ Achievements
28/08/22	Completed 4.5m Bridge to Brisbane, had large pneumothorax in right lung. Admitted to ED.	Had chest tube drain inserted, admitted to heart & respiratory ward.
30/08/22	Thoracic surgeon consulted to do a pleurodesis surgery while I had my drain in. After surgery I was immobile for a few days with tubes attached to each arm, and the chest tube on the right side of my body & stitches.	Pleurodesis right lung completed successfully. Enjoyed the company of several visitors every day.
1/09/22	Physiotherapy commenced once arm tubes could be removed & I could push vitals stand machine and carry the drain simultaneously. Used suction tube to hold up balls device to exercise my lungs directed by physio.	Walked around the ward a few times a day. To hold up max 3 balls in the device that required reasonable lung capacity and breathing strength achieved on 03/09 much to the physio’s delight. I have kept this device to use weekly.
03/09/22	Discharged from hospital with instructions to rest at home with no driving or exercise for 3 weeks to let my stitches & lung heal.	07/09 started working again from home, went back to strict healthy eating, slept more to recover.

10/09/22	Had my first social outing with hubby. We went to Gallery of Modern Art and out for lunch.	Chiharu Shiota art exhibition was amazing! Started outdoor 2km walks.
20/09/22	My GP took out a butterfly stitch and checked my breathing. Cleared to go back to the office and exercise again.	Resumed regular exercise regime at medium pace, combo at home: cycling bike, treadmill walking and core mat Pilates. 20 min sessions every alternate day.
26/09/22	Returned to work at head office and going out more for social events and activities.	Life resumed at hectic pace, set 3 months' weight loss and fitness program with exercise buddies. Working out on weights added to cycling, brisk walking and core mat Pilates 5 times a week.
31/01/22	After CT chest scan & appointment with respiratory specialist including lung function test. Cleared to resume air travel.	04/12/22 Flew to Victoria for work and back & physical worked on construction site with no issues. 20/12/22 Achieved 3.5 kg weight loss and fitness goal levels just in time for Xmas/NY break!

For those who wish to join the next **Brisbane LAM friends lunch on Thursday 9th February 2023,** please see the details below to RSVP. We are excited to have our president Louise Lloyd join us! With best wishes, Corrine social@livingwithlam.org

PLEASE JOIN US
(LOUISE LLYOD VISITING FROM NSW)

Brissie LAM Lunch

THURSDAY 9TH FEBRUARY 2023

When: 11:00am - 1:00pm
Where: Hotel Beach House - Garden City
Town Square Westfield Garden City
Info: https://beachhousegardencity.com.au/

RSVP: by 02/02/2023 to Corrine: 0413 563 526

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LAM Medical Updates

If you missed the last LAMposium webinar:


LAMposium in your Living Room recording is now available

https://www.thelamfoundation.org/The-Latest/Article-Details/Article/414#article

Research into Pelvic Floor Dysfunction and LAM

Please complete a brief anonymous survey

Mary Beth Brown, PT, PhD Associate Professor, Director of Research, University of Washington

Department of Rehabilitation Medicine Division of Physical Therapy Health Sciences Building BB-826 | Box 356490 | Seattle, WA 98195 206.685.3852 | mbbrown1@uw.edu

From Beth: My lab is currently collecting electronic survey data **investigating incidence and impact of pelvic floor dysfunction in LAM**. The survey builds on data recently published for CF and COPD by researchers in Australia, and we'll add LAM data to that same data set to allow comparisons.

The Brown lab would like to ***invite individuals with LAM*** *who are between the ages of 18-80 years to complete a brief research survey focused on assessing the incidence and impact of UI. The survey should take 5-10 minutes to complete.* ***Please note that you do NOT need to have any symptoms of urinary incontinence (involuntary loss of urine) to take the survey****. We are hoping to survey as many individuals with LAM as possible to get a representative sample. This survey is anonymous and so please do not include any identifiable information (e.g. name, date of birth, e-mail) in your response. Thank you for your time and participation in our study!*

Here is the link to the survey:

https://redcap.iths.org/surveys/?s=DYPKCDHTLK8773JA

An extract from: The Laboratory of Dr. Mary Beth Brown in the Department of Rehabilitation Medicine at the University of Washington, Seattle,

Urinary incontinence (UI) is extremely common in women and is reported to have significant negative impacts on quality of life and long-term health outcomes. Pulmonary disorders are considered to be a risk factor for UI. Higher rates of UI have been reported in populations with chronic pulmonary disease including in a recent study in Australia (Button et al, 2019) which found that women with chronic lung disease are twice as likely to develop incontinence as compared to healthy populations, and that it imposes considerable psychological impact in this group.

To date, UI has not been systematically assessed in women with Lymphangioleiomyomatosis (LAM) and data regarding incidence and impact is not currently available. The Brown lab is currently collecting data using a similar questionnaire utilized by Button et al (2019) to permit responses to be directly compared to COPD and CF data reported in that study and their matched healthy groups. Studying the prevalence of UI in LAM provides an opportunity to better understand if investigation of UI and pelvic floor interventions in LAM is warranted.

Member Stories: *Sharing Stories to Raise LAM Awareness* by Penny McKee,

Living with LAM Committee member

Penny and her family in Port Macquarie, NSW January 2023

Before I begin: I'm behind the delay in the Jan newsletter! Apart from the usual family antics, study and work, our eldest is leaving for uni in a few weeks and husband Cameron will be working in the Hunter Valley during school term. My apologies to you all and my thanks to the committee for their patience!

Living with LAM Member Stories: Penny McKee

Hello everyone

You may know that I’ve made a few attempts at reaching out to various women focused companies (hello Mamamia and Lorna Jane!) to seek a partnership whereby we can work together to raise awareness of LAM. Many of you kindly shared your experience of living with LAM that was included in that reach out.

I’m still persevering with this project, however given that **Rare Disease Day** on **February 28** is just around the corner, I thought I’d share with you the communication I have sent to these companies. You may wish to use some of this content in your own reach outs and awareness raising at your workplace, with your community or friends and family, especially in the lead up to Rare Disease Day.

People connect and take action via stories. I’ve included part of my LAM story and you’re welcome to use, edit or delete accordingly to accommodate your own story if you wish.

Warm regards, Penny

Here’s an extract from the sample:

Begin Sample: LAM is a rare beast.

It affects around 4-6 women in a million.

There’s about 100 diagnosed cases in Australia, and it’s likely your GP has not heard of it.

Thanks to research undertaken by LAM Australia and overseas largely funded by patient run organisations and fundraising, we’ve come a long way since the bleak projections of 1995. A treatment has since been identified which has been successful in slowing the progression of LAM.

But it is not a cure.

We’re still short of breath. And short of research funds.

So, I write because due to the rarity of this disease, raising awareness of LAM is crucial and critical in achieving a correct and timely diagnosis so that medical intervention can occur.

I write because raising awareness of LAM is crucial and critical to achieving funding for research.

I write because raising awareness of LAM is crucial and critical in achieving awareness of organ donation for future lung transplant recipients.

I write because **Rare Disease Day is coming up on 28 February.**

On behalf of Living With LAM, I warmly welcome your contact to discuss LAM and its impact on Australian women. We are a brave tribe with different LAM stories that we'd love to share in the hope that we might make a difference for future generations of women living with rare diseases.

We might be short of breath, but we're not short on guts.

(Your name here) **End Sample.**

Member Stories: If you are recently diagnosed OR in the transplant world (work up / post-transplant or dithering like me) we'd love to hear from you for inclusion in our **May newsletter** to correspond with **Donate Life** month. Please contact Penny on FB or at thevowfactor@gmail.com

For your Diary:

28 February: Rare Disease Day

May: Donate Life Month

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Wording for will bequests:

Examples of bequest wording for a gift to LAM Australia Research Alliance (INC: 9886298 / ABN: 1252 891 9171)

1. Specific Purpose Bequest

I give to the **LAM Australia Research Alliance** (ABN 1252 891 9171), [the whole of my estate] or [x% of /the residue of my estate] or [the sum of $________] free of all duties and taxes thereon. I express the wish but without creating any binding trust that if practical this gift be applied toward______. I declare that the receipt of the President or other authorised officer of the charity, will be sufficient discharge for my trustees.

2. Directed Purpose Bequest

I give to the **LAM Australia Research Alliance** (ABN 1252 891 9171), [the whole of my estate] or [x% of /the residue of my estate] or [the sum of $________] free of all duties and taxes thereon and direct it be applied for [please state the purpose/s as widely as possible to avoid any difficulty in application]. I declare that the receipt of the President or other authorised officer of the charity will be sufficient discharge for my trustees.

3. Unrestricted Bequest

I give to the **LAM Australia Research Alliance** (ABN 1252 891 9171), [the whole of my estate] or [x% of /the residue of my estate] or [the sum of $________] free of all duties and taxes thereon and direct that it be applied for the general purposes of the charity in such a manner as the Committee of the charity may determine. I declare that the receipt of the President or other authorised officer of the charity will be sufficient discharge for my trustees.

Bequests to the **LAM Australia Research Alliance** (ABN 1252 891 9171), are exempt from the payment of both Commonwealth Government and State estate duties.

The Back Page

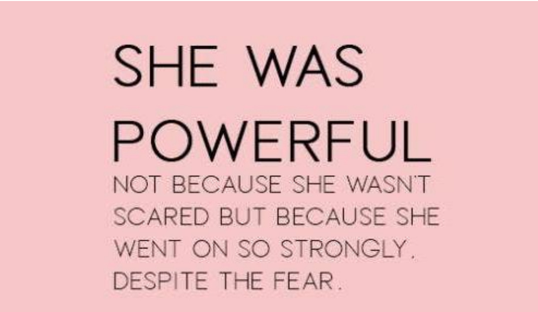
New to the LAM community?

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:



SHE WAS POWERFUL NOT BECAUSE SHE WASN'T SCARED BUT BECAUSE SHE WENT ON SO STRONGLY, DESPITE THE FEAR.

Your friendly Living with LAM Committee:

President: Louise Lloyd

Vice President: Corrine Tye-Lim

Secretary: Alison McIvor

Treasurer: Lauren Sharpe

Committee: Pat Evans | Penny McKee | Dr Sukhwinder-Sohal | 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.