



Supporting women living with lymphangioleiomyomatosis (LAM)

October Newsletter 22



Hello everyone,

I do hope you are all ok following the devastating floods that we have been through and that we have seen the last of them for a long time.

Over the last couple of months we have been focusing on developing a member database to register our member's data securely and to enable information to be held that could potentially be used in research. Please be assured no data will be released from the database at any time without your prior approval. We shall be asking you to check the data we have in the database to ensure it is up to date and accurate. We will be sending members a special gift to the address we have listed on the database, so please make sure it is correct!

We continue to work with our researchers both here and in NZ where positive work and outcomes are being made. Thank you to everyone that has made donations that have contributed to these research outcomes.

I just wanted to give a big thank you to Corrine for her efforts doing the Bridge to Brisbane walk – over \$1,400 was raised and as we found out later she did it all with a collapsed lung which required hospitalisation and a pleurodesis procedure. So good to see her recovering well and back on her feet....

All the best,

Louise Lloyd

president@livingwithlam.org

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



On Sunday 28th August 2022, I completed the 4.5km Bridge to Brisbane Fun Run event with a team of family friends and enjoyed walking, talking & laughing along the way. At the start line Living with LAM was mentioned by the host on microphone who noticed our t-shirts to raise awareness.



That's our Corrine (40288) at the Bridge to Brisbane Fun run in August 2022

Thank you to everyone who supported the team to help us raise \$1400 in funds for LAM research. This year we remembered to stop by the stall to collect our medals after collecting our free mandarins & bananas.





My personal twist to this year's B2B - I was not aware that I completed the 4.5km with a large pneumothorax in my right lung. After the post-event cocktails team lunch, I asked my husband to drive me to ED (as I was due to fly interstate for work on Tuesday).

A scan in ED confirmed my predicament. With an immediate chest tube drain procedure, and my specialist deciding to send in a thoracic surgeon I ended up having a Pleurodesis surgery. Now I know during the pleurodesis surgery you are turned like a rotisserie chicken to one side for access to the lung and the medical talc process.

I have fully recovered and am back to normality - driving, exercise, working at the office and going out with family and friends. Thank you to the wonderful support from my LAM sisters during this journey, you really all brightened my hospital stay.

Corrine

Vice President - Living with LAM

LAM Medical Updates

[Your Lung Function Test Results \(LFT\): An Explanation from Dr Andreas Fiene,](#)

Dr Andreas Fiene is a thoracic, transplant & sleep physician. He is particularly interested in chronic respiratory illnesses & their influence on breathing & related sleep disorders.

Contact: North Brisbane Sleep & Thoracic Ph 1300 391 820 Email reception@nbst.com.au

Patients with LAM can have a variety of abnormalities on their lung function test results.

- Normal spirometry (30 to 60 percent)
- Obstructive pattern on spirometry (25 to 66 percent)
- Restrictive or mixed obstructive and restrictive pattern on spirometry (less than one-quarter)
- Reduced DLCO (60 to 90 percent)

About a third of LAM patients demonstrate reversible airflow obstruction following an inhaled bronchodilator. (Salbutamol)



- Lung volumes may be elevated in LAM (due to hyperinflation), resulting in an increased total lung capacity (TLC), residual volume (RV), and RV:TLC ratio. However, lung volumes may also be normal or reduced.

Diffusing capacity is reduced in many patients with LAM, even in those with normal spirometry.

Your physician will identify the abnormality at time of diagnosis and then monitor your individual abnormalities. A reduction in the FEV1 might be transient and affected by infections, asthma or weight gain for example.

Worsening results of the lung's diffusion DLCO capacity are more likely to indicate disease progress and might trigger a physician to start treatment or consider lung transplantation.



Member Stories

Roberta Matai visits LAMPOSIUM, Chicago 2022



<https://www.uts.edu.au/staff/jobs-at-uts>

Roberta at the 2022 LAMposium in Chicago, August 2022.

The 2022 International LAM Research Conference & LAMposium last month at Chicago USA was an amazing experience. The theme was ‘Together we R-I-S-E’ – Research Innovation Support Engagement. Approximately 125 LAM patients attended from all across the United States, United Kingdom, Sweden, France, Central and South America, and of course Australia.

The 2+ day program was jam packed with interactive sessions, casual social sessions, and time to recharge. The LAMposium provided a unique opportunity to have free consultations with doctors and researchers. They were happy to share their research and answer questions during the sessions, in the dedicated research room, and during meal breaks.

The climax of the LAMposium was the magnificent Breath of Hope Gala. It was phenomenal to witness the generosity of the LAM community which raised over US\$450,000 for LAM research that evening!

I am immensely grateful to have received the SOFTA travel grant to give me the opportunity to travel to the conference. I was delighted to meet for the first-time other patients in-real life and to experience the generosity and warmth that each Lammie provides in sharing their stories and supporting your story.

I encourage my fellow Australian and New Zealand Lammies to attend future LAMposiums. It truly is a worthwhile experience that will encourage you and provide hope for your lymphangioleiomyomatosis journey. Roberta Matai



The LAM Foundation would like to announce that our next Circle of Hope (COH) social gathering is scheduled in local Sydney Australia time of Monday, November 7 at 9:30am AEST. Below is the registration link. I hope you can join us!



Our COH Medical Director and LAM Clinic Director at the Loyola University Medical Center, Dr. Dan Dilling, will join us for the first 30-40 minutes to discuss a review article recently published in The Journal of Heart and Lung Transplantation. You can find the review abstract [here](#). This is a fantastic opportunity for us to hear from the author himself as the full article is not yet available in PDF or without subscription to the journal.

We will also allow time for Q&A. Please submit your questions for Dr. Dilling in advance, which helps me to organize them by topic and share with him ahead of time.

Following Dr. Dilling's time with us, we will move into group discussion. I look forward to welcoming new members to our group and catching up with all of you. If there is a specific topic you would like discussed and/or a question you would like posed to the group, please let me know in advance.

Again, I look forward to seeing you all soon!

Date: local Sydney Australia time of Monday, November 7

Time: 9:30 a.m. – 11:00 a.m. AEST

Registration Link: [Register Here](#)



New to the LAM community?

Become a member: <https://www.livingwithlam.org/a-test-form/>

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

Make a donation:

Please consider making a donation (fully tax deductible) to help support our members and to fund research into finding better health outcomes for those living with LAM....thank you:

<https://www.livingwithlam.org/donate/>



The Living with LAM Committee:

President: Louise Lloyd

Vice President: Corrine Ty-Lim

Secretary: Alison McIvor

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