



“Supporting Women Living with Lymphangiomyomatosis”

NEWSLETTER JULY 2022



LAM Australia President’s Report:

Hello everyone,

I’d like to thank our members that joined us for the Annual General Meeting. At the meeting the new committee were elected as follows:

Executive Committee:

- President – Louise Lloyd (2 years)
- Vice-president - Corrine Tye-Lim
- Secretary – Alison McIvor
- Treasurer – Lauren Sharpe

Supporting Committee:

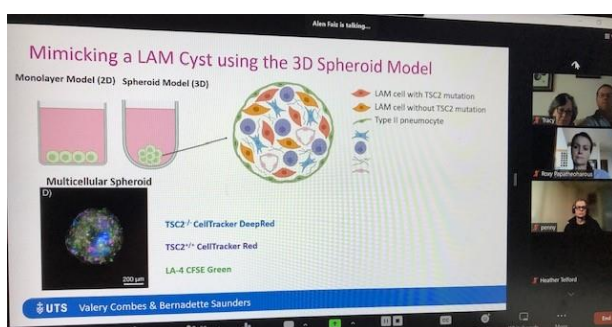
- Penny McKee
- Dr Sukhwinder
- Kate Wingrave
- Pat Evans

Additional information and reports from the AGM can be found on our website:

<https://www.livingwithlam.org/annual-general-meeting-2022/>

I would like to thank our outgoing committee members for their support and commitment over the years, it is much appreciated and, to welcome our new members and thank them for volunteering to help us to support our members.

At the AGM we had a presentation by Dr Alen Faiz, Senior Lecturer, School of Life Sciences at the University of Technology Sydney (UTS). Dr Faiz discussed the research work currently being undertaken by the Science Faculty team at UTS on the origin of LAM cells, the build of a 3D model of a LAM cell that has been developed which will help with ongoing research, and the search for a biomarker of LAM from blood samples that will provide an early, low-invasive diagnosis. There is a team of researchers working together globally on some very exciting research that will provide better health outcomes, better quality of life and, hopefully one day a cure for LAM. We thank Dr Faiz, Valery Combes and Bernadette Saunders for their work on LAM and for joining us at the AGM.



Research is so very important to providing better health outcomes for us – a good example is the re-purposing of Rapamycin (Sirolimus) for use with LAM, since its introduction as a medication for LAM in the UK over the last 4 years there have not been any lung transplants for LAM patients. We need to continue this work and support our researchers in their quest to support and assist with not only better health outcomes but for a cure for LAM.

In June we held a 'Night of Magic' event which was a free event to thank our members and supporters for their ongoing support and assistance. The magician – Ben had us all amazed and asking 'how did he do that??' – a fun night and a great show!! There is a small video of the event which you can access here (copy and paste into your browser): https://drive.google.com/file/d/12-siqyrs_GBsGsQF93WggHiTdx9w4ks/view?fbclid=IwAR2XvgL_fJa2pGM4xtPvRndH4Rwm0wQYb11o2KgXiU3157bXnA_HgehNRRc



We continue to build a global community and I have recently had meetings with our counterparts at the LAM Foundation and LAM Action UK. These meetings allow for information/ideas sharing, and a combined effort to build awareness, seek research grant funding globally and provide support to each other in our quest to support our members.

Thank you also to everyone who has made donations to LAM, we couldn't provide our support, fund research or build awareness globally of LAM without your kind support.



We now have the "Registered Charity" tick showing we are listed on the Charity Register at the ACNC. If you would like to make a donation the link is:

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

Our priorities for the coming year are to provide support to our members, build a strong global community and fund research to find a cure for LAM.

We shall hold more online events this year and I would really like you to let us know the topics and discussion points you would like included. These sessions are to provide you with information, knowledge sharing and to provide insights into living with LAM for our members, their family and friends, so we need your input and suggestions – send your suggestions to:

social@livingwithlam.org

Please note that due to increased COVID and flu cases currently, the planned walk on Sunday 28th August 2022 has been postponed.

I thank our auditors Loggica Pty Ltd for their ongoing support, the contributors to the newsletter, and our volunteer committee for their assistance and support it is much appreciated.

All the best,

Louise Floyd x

Contact: president@livingwithlam.org



LAM Australia Vice President's Report:

Hello everyone,

I am writing to you all from my holiday in Perth, a much-needed break from work after 1.5 years, and an emotional and happy reunion with my family whom I have not been able to visit since September 2019 due to Covid19 travel restrictions to WA.

I will be back in Brisbane to host a team for the 4.5km Bridge to Brisbane course (pink walkers) on Sunday 28th August 2022. If you would like to participate in our team virtually or physically, please register with these steps:

1. <https://enterb2b.com.au/enternow.aspx>
2. Choose Join a Team

Welcome to the 2022 The Sunday Mail Transurban Bridge to Brisbane August 28, 2022

Individuals & Small Groups

Use this option to enter as an individual.

You can register others too and pay all at once.

Individual Entry

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

3. Fill in your personal details, choose the 4.5km option

Please select the race you would like to enter by clicking an 'Enter' button.

Bridge to Brisbane 10km Race
Bridge to Brisbane 10km Race
Enter Bridge to Brisbane 10km

Bridge to Brisbane 4.5km Race
Bridge to Brisbane 4.5km Race
Enter Bridge to Brisbane 4.5km

4. Under Team Entry details, select Living with LAM Fam in the drop down box (no pin required) and select Pink Walker, fill in your personal information

TEAM ENTRY DETAILS ● = These questions require a response.

Please untick if you are NOT joining a team.

Type to search for your team name: Living with LAM Fam ● ●

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

STARTING ZONE

Starting Zone: Pink Walker - Over 45 min ●

PERSONAL INFORMATION

5. Complete and pay for registration. Please note B2B already has a registration fee. However please share with your network of friends, family and colleagues to support the fundraising event with this link: <https://www.gofundraise.com.au/payments/donate/beneficiary/1373067>

Corrine Jye-Lim x

Contact: corrinet@hotmail.com M: 0413563526

LATEST UPDATE ON ANTI-VIRAL COVID-19 MEDICINES – Thank you to DR Jeff Lindemayer

If I catch COVID19 while I'm taking Rapamycin for LAM which anti-viral medication should I take, Paxlovid or Lagevrio?

The short answer: molnupirovir, sold under the brand name 'Lagevrio'.

Your GP or Respiratory Physician can prescribe Lagevrio if you've had symptoms of COVID19 for 5 days or less AND you have had a positive COVID19 RAT or PCR test since you became unwell. The sooner you commence Lagevrio the better it works, so if you develop a fever, sore throat, cough, muscle aches, loss of smell, diarrhoea or any combination of these symptoms you should get tested as soon as possible.

Here are your choices:

- If your symptoms are mild, perform a Rapid Antigen Test (RAT) at home. If it is negative, repeat it each day for 3 days. RATs often test negative early in the infection.
- If your RAT is positive you need to talk to a doctor to discuss commencing Lagevrio. This could be a phone consultation with your GP or specialist. Alternately, call a COVID Respiratory Clinic for an appointment or advice. To find a COVID Respiratory Clinic in your state: <https://www.health.gov.au/initiatives-and-programs/coronavirus-covid-19-gp-respiratory-clinics>
- Your doctor may send a prescription to your mobile phone, or fax it to your pharmacy. Of course you'll be required to isolate after testing positive so ask a friend to collect the medication or get the pharmacy to deliver it.
- You should also notify the Health Department in your state of your positive RAT or PCR result. They will call you to check how you're recovering and offer assistance. To notify a positive result by phone, call 1800 020 080 or go online at <https://www.health.gov.au/health-alerts/covid-19/testing-positive>
- If your symptoms get worse each day, or if you have a fever over 38.5 C, or are coughing up thick or bloody mucus, you need a face-to face consultation with a doctor, even if your RAT or PCR is negative.
- If you have a pulse oximeter which shows your oxygen saturation has fallen below its usual level you may need to be admitted to hospital for intravenous antiviral drugs and oral cortisone. Ideally your GP or Respiratory Clinic will liaise with the hospital before you arrive. Some Emergency Departments have a separate area for patients with COVID19, so call first. If you are having difficulty breathing call an ambulance on 000.

If I'm prescribed Lagevrio how do I take it?

Lagevrio is a brown capsule which must be swallowed whole. Each capsule contains 200mg of molnupirovir. You should take four capsules each morning and four each night for 5 days. Side effects can include nausea, dizziness and diarrhoea.

I've heard Paxlovid is a better treatment for COVID19. Why can't I take that?

The short answer: Paxlovid might increase the Rapamycin in your blood to toxic levels.

Paxlovid is actually two drugs taken at the same time, and one of these drugs blocks the breakdown of rapamycin in your liver. This could cause a build up of rapamycin in your blood, even if you stop taking rapamycin.

How do anti-viral drugs work? Can COVID come back?

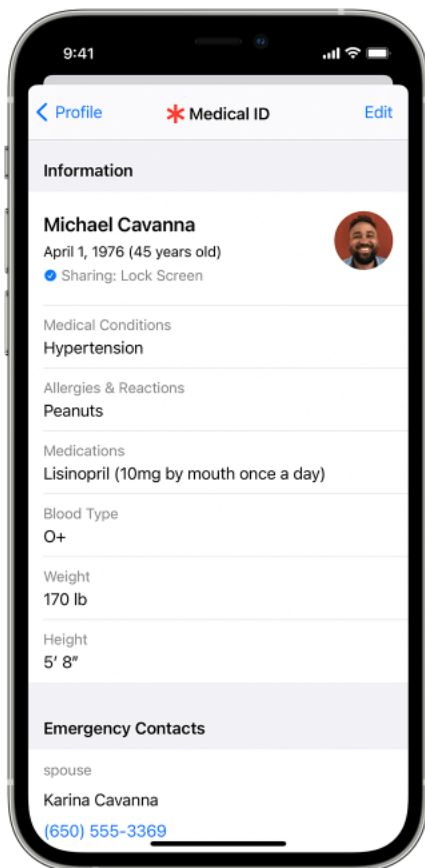
Lagevrio and Paxlovid stop COVID19 replicating within infected cells. After you complete your five-day course there may still be intact viruses in your airways. These viruses sometimes reactivate to cause a second wave of COVID infection, as occurred recently to President Joe Biden. You still rely on your immune system, ideally boosted by 4 or more vaccinations, to eradicate the infection.




MEDICAL ID

A medical emergency can happen, and it is important that the first responders have access to critical medical information – it could save your life.

On Apple devices (iPhone, Apple watch) you can setup your Medical ID which emergency responders can access even from a locked screen without needing your passcode. They can see information such as your medical conditions, medications, as well as who to contact in case of an emergency:



How to set up your Medical ID

1. Open the Health app and tap the Summary tab.
2. Tap your profile picture  in the upper-right corner.
3. Under your profile picture, tap Medical ID.
4. Tap Edit in the top right-hand corner.
5. To make your Medical ID available from the Lock Screen on your iPhone, turn on Show When Locked. In an emergency, this gives information to people who want to help. To share your Medical ID with emergency responders, turn on Share During Emergency Call. When you make a call or send a text to emergency services on your iPhone or Apple Watch, your Medical ID will automatically be shared with emergency services.*
6. Enter health information, such as your date of birth, allergies and blood type.
7. Tap Done.

If you do not have an Apple device there are apps available for use on Android phones:

Google Play has an app called – Medical ID



Medical ID (premium)
Laurent Pellegrino
4.7 ★ \$5.49

Additional Apps include: ICE and Medication List & Medical Records apps.

These apps hold your medical information, contacts and even show your location.

Let your family and friends and your medical team know that you have setup your medical ID on your device, so they are able to pass on this information if they are contacted.

Hopefully you will never need to use this facility, but it is good to know it is available if needed!

ENTERTAINMENT MEMBERSHIP FUNDRAISER (Kate Wingrave, LAM Committee Member)

Support us in the month of July and you will automatically receive a 2 month extension of your Entertainment Membership when you purchase a 12 month product.

That is an extra 2 months for **FREE** (14 months total) to use and save with your Entertainment Membership!!

And what's even better 20% of every membership purchased goes to Living with LAM.

<https://subscribe.entertainment.com.au/fundraiser/91310b>



ISOLATED PATIENT TRAVEL & ACCOMMODATION ASSISTANCE SCHEME:

IPTAAS is the Isolated Patients Travel and Accommodation Assistance Scheme. This is a NSW Government scheme providing financial assistance towards travel and accommodation costs when a patient needs to travel long distances for treatment that is not available locally.

From 1st August 2022, there will be the increased assistance for rural & regional patients applicable. The process is more streamlined and easier to claim reimbursement for medical travel, if you need to travel with a carer, an additional allowance is available for them. This is great news for NSW regional and rural LAM ladies making trips to Sydney!

<https://www.iptaas.health.nsw.gov.au/For-patients>

LIVING WITH LAM MEMBERSHIPS: <https://www.livingwithlam.org/join-us/>

Thank you to everyone who has registered or renewed their membership with payment. A big warm welcome to all new members on behalf of the Committee. We will be sending out a member pack to each member in September that contains our new logo collateral – a shopping tote, water bottle, happiness journal & pen plus updated informational flyers about LAM which you can keep for yourself and also pass to your GP.