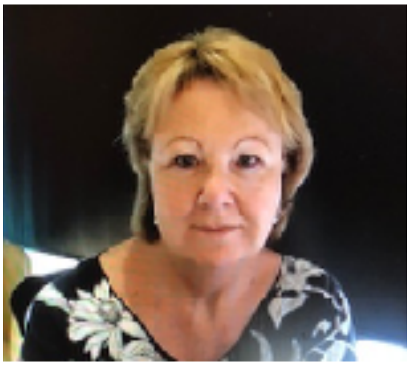
LAM AUSTRALIA
RESEARCH ALLIANCE
SEEKING A CURE FOR LAM
LYMPHANGIOLEIOMYOMATOSIS

http://www.livingwithlam.org

"Supporting Women Living with Lymphangioleiomyomatosis"

# NEWSLETTER March 2022



LAM Australia President's Report:

Hello,

I'd like to thank everyone who joined us for the Rare Disease Day Panel discussion on Living with LAM. We had a great turnout of attendees and our panel members – Prof. Brian Oliver, Dr Deborah Yates and Ana Paula Ruiz, were just amazing. To have taken the time to join us, present and be available for questions was very much appreciated and we thank them.
Thank you also to everyone that made a donation to LAM, your kind support will be used to help support research into LAM and to supporting those living with LAM and their families.
The discussion items covered by the panel included LAM in the Lab, Medical Management of LAM and Ana's story of her Lung Transplant Journey (if you would like a copy of Ana's slides and coping tips please let me know and I will send them through to you):

LAM: clinical presentation

The session was recorded so if you missed the live session please use the link (copy and paste into browser) and passcode below to watch the panel discussion:

Meeting Recording:
https://uni-sydney.zoom.us/rec/share/VLCiNia_v_5R7ld_Nu5lIQvxXV2bR53Sf0ZtKy8acxYGNKT4h9eNo2sPYhaM3LB0.XiLGmDzJSqntheJj

Access Passcode: 2z?qh#h7

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 e.g. Coping with Fatigue / Your Children and Your LAM / I've Just Been Diagnosed with LAM. What Happens Next? Since My Diagnosis / COVID in the

House…..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

Just a reminder to all that we now have LAM Peer Connect. Working with the Lung Foundation of Australia we have put together a support program for patients and caregivers/families to connect with other women living with LAM. Register your interest in joining the program: https://www.livingwithlam.org/support-contact-list/

This year we have already been busy:

- Supporting Rare Disease Day
- Arranging for Dr Helen Whitford (Respiratory Physician at Alfred Hospital Melbourne) to be interviewed for a medical podcast on LAM. The podcast is being produced and distrusted to GP's and the primary care community of Australia by Healthed Australia – the largest independent provider of medical education in Australia. As one of our priorities is to raise awareness of LAM throughout the medical community this is a great opportunity and we are extremely grateful to Dr Whitford for agreeing to be our expert for the podcast interview. We shall receive the podcast and place it on our website as soon as available.
- Continuing discussions are taking place with the LAM Foundation to build a stronger alliance and we thank them for their support and guidance. The LAM Foundation has been very supportive and we look forward to enjoying a long and beneficial relationship with them into the future.
- Wondering which mask to use – hear from our own Professor Brian Oliver: https://www.facebook.com/watch/?v=426242301612635
- We have setup a new Facebook page – Living with LAM Australia – please join the group https://www.facebook.com/groups/562655918520170
- The website rebuild continues with a new theme and fresh new look, please let us know what you would like included on the site – www.livingwithlam.org

**A special call out for assistance…we need your help!
If you are or know of a graphic designer that can help us with graphics for our new tote bags, caps and brochure please contact us at social@livingwithlam.org.

I thank the committee for their assistance and support which is invaluable.

It looks like we are moving towards being able to meet face-to-face and I look forward to being able to meet you all in the near future - until then we shall continue to work towards providing improved health outcomes whilst keeping you supported and informed.

All the best,

*Louise Lloyd x*

Contact: president@livingwithlam.org

# SAVE THE DATE – Sunday 28 August 2022

We are planning a national walk on Sunday 28 August 2022 in support of our members living with LAM, their family and friends. Bring your family, bring your friends and have a lovely day out enjoying the beautiful outdoors.

The theme for the walk with be:

**Will You**
**Walk**
**With Me**

In Sydney we will meet on the steps of the opera house and walk to the Harbour Bridge which we will cross and then return to the Opera House. This is a self-paced walk and you can join in or leave at any point as we shall have marshals at intervals along the way to help you with directions. The walk will start at 10:00am which will allow everyone after the walk to spend time with their family and friends perhaps have lunch at the Opera Bar or at the many restaurants along the harbour foreshore. In Brisbane this coincides with the Bridge to Brisbane walk so sign up for fundraising.

We will organise similar walks and virtual walks in all major cities and weather and COVID permitting, we will have the chance to come together and walk in support of women living with LAM.

Registration for the walk will be $25 however for families you only need to register once, on the day those registered will receive a Living with LAM tote bag filled with useful bits and bobs for the walk.

Looking forward to seeing you on the walk – watch for updates and more details coming soon!

## SUPPORTING OUR MEMBERS

Introducing a beautiful artisan range of silk linen pillow slips, wraps, sleep slips in travel pouches that care for the planet and combining the best of both materials to help you sleep better and longer. The founder of SoSsleepponsilk is Debra Bowen, Designer, Photographic Stylist and Sleep Enthusiast.  Debb is part of our Living With LAM family who has inspired us with her lung transplant journey.
For the month of April $20 from every sale will be donated to livingwithlam.

https://sos-sleeponsilk.com/

## LATEST UPDATE ON ORAL COVID-19 MEDICINES FACTSHEET (NPS MedicineWise)

Summary: Oral medicines to treat Covid-19 are now available in Australia, Lageviro & Paxlovid. These are antiviral medicines taken as tables or capsules that work by stopping viruses in your body from copying themselves, with less copies of the virus in your body, your chance of getting very sick is lower.

There are special criteria of patients for doctors to prescribe these medicines, which are effective if taken within five days of getting Covid-19. Please speak to your doctor to see if these medicines are suitable.

Vaccination is the best way to protect yourself and the health of your loved ones against Covid-19.

A friendly reminder winter is coming in a few months and now is the time to organise flu vaccinations, Covid-19 vaccination boosters and pneumonia vaccinations if eligible.

See the Fact Sheet:  https://www.livingwithlam.org/oral-covid-19-medicines/

LAM Australia Vice President’s Report:

Hello,

It has been a unique start to the year, seeing through the peak of Covid19 in lockdown and the floods in Brisbane. Have spent a lot of the last three months working from home. Without the rushing around and commuting in traffic (apart from school drop offs) it meant I had more quality time to spend with my family, exercising (I completed a 5 weeks’ challenge with an exercise accountability buddy to get into shape for a personal photoshoot project), cook new recipes and make new cocktails!

Sharing my favourite cocktail and Thai salad recipes that were definitely easy & successful:
https://www.recipetineats.com/green-papaya-salad/
*Note I used fresh green paw paw and fresh herbs.
https://lovelyindeed.com/gin-and-prosecco-cocktail/ my personal twist was adding fresh mint!
And a lovely recipe idea from Kate Wingrave:
https://shewearsmanyhats.com/black-bean-mexican-salad/?fbclid=IwAR1_8JBwvs47VqGZpcU0D0M8YvXN5kdIYQAnL7xiseu5CSsr7xLnfXcXgxs

During this time I had an idea to put together a weekly journal template, a resource for people to write as a way to slow down, check in with themselves and practice mindfulness and gratitude at whatever stage in life they were going through.

Please see the template at https://www.livingwithlam.org/happiness-journal/ which is divided into two chapters. Chapter 1 explores Self Love (your heart), Self Love (your body), Self Love (your mind) and Love to Others (relationships). Chapter 2 is a daily journal for Monday – Sunday. I encourage you to take a look.

“The journey isn’t about becoming a different person. It’s about loving who YOU are right now” – Suzanne Heyn

I am in the process of organising some fun casual online events for our community and would love your ideas. So far the most popular are:
1. Virtual Cocktails Around the World Night (Mocktail versions included)
2. Guess the Song or Guess the Movie
3. Trivia

If you are a member and would like us to promote your business in our newsletter we would be happy to support you.

Please email me your ideas: social@livingwithlam.org
Best wishes, Corrine Tye-Lim x