



## Season's Greetings & Happy New Year

07 December 2016

LAM Australia Research Alliance wishes women living with LAM, their loved ones, those who care for them, and their supporters all the best for the festive season and for the year ahead.

Please have in your thoughts and prayers brave Amy Evans of Queensland. Amy has now been on the lung transplant list for 43 weeks, waiting to replace the donor lungs which allowed her and her husband, Jeremy, to delight in the development of twin daughters, Dani and Jenni, from 1 year-olds when Amy was diagnosed with LAM, to 11 year olds who just graduated from primary school. The Evans boys, James and Tom, are 16 and 17.

For women living with LAM, turning the corner into a new year means adding another year of hope since the onset of the disease. It's positive to report that an increasing number of LAM cases are responding to the drugs now available – chiefly everolimus and sirolimus. Research gives hope to women living with LAM, whether newly diagnosed, or having lived with LAM for many years. When research brings a better understanding of this strange, rare disease, targeted treatments will follow.

Fundraising for research is a chief objective of LAM Australia. Research is time-consuming and expensive. Over the years, we have been supported with major grants and with money raised in on-line campaigns and through many events. These include a film night, walkathons, a trivia night, a beach walk and BBQ, Entertainment Book and chocolate sales, a yogathon, a gym day, and COMING UP, the raffle of a quilt and an 80s dance party!

Raising funds has benefits beyond the monetary – it raises awareness of LAM and it empowers those who get involved. We hope you'll be inspired by the fundraisers organised by Barbara Cameron and Kate Wingrave to play a part in raising funds for research.

**Kate's 80s Dance Party**  
18.02.2017, Perth WA

**Cobargo Handmade Quilt**  
Raffle Draw 22.12.2016



Our top fundraiser, Kate Wingrave, and Donna Albertini are organising a fabulous dance night with popular band, The 80s Underground. To be held on Saturday 18 The February at the Leopold Hotel, in Bicton, Perth, the night will include a raffle, silent auction and door prizes. Proceeds will fund LAM research.

Barbara Cameron is selling tickets for a beautiful handworked quilt created by the Cobargo Quilting Group. The queen size cotton quilt will be raffled 22 December 2016 to raise funds for LAM research. Tickets are \$2 each or 3 for \$5. Email [admin@lamaustralia.org.au](mailto:admin@lamaustralia.org.au) to order tickets and advise of your payment to the LAM Australia Research Alliance bank account: 012-055 4926 67193. Alternatively, you can pay into Kristy Hope's special raffle account: [PayPal.me/kristyhopePayPal.me/kristyhope](https://www.paypal.com/au/m0/beneficiary/kristyhope). Email Kristy to advise of your deposit and order tickets [kristyhope@hotmail.com](mailto:kristyhope@hotmail.com).

## News from our President, Dr Brian Oliver

### RESEARCH

With the generous support of the Roth Foundation supplementing money donated and raised more widely, LAM Australia is now funding the most exciting LAM research project proposed in Australia. Involving genomic research at the cutting edge of worldwide research, it is a collaboration of the world-leading Garvan Institute <http://www.garvan.org.au/news/news/the-future-of-genomic-medicine-has-arrived-in-australia> and the Woolcock Institute <http://woolcock.org.au/lam-research/>. The goal of the research is to identify and find a way to switch off the genetic code that causes LAM. Research findings may lead to earlier, more effective treatments.

### SLAM

Under my direction, pre-med students at the University of Technology Sydney (UTS) formed Students for LAM (SLAM) in 2015. SLAM has two aims: to raise funds for LAM Research and to provide plain English summaries of the latest LAM research projects worldwide. Stephanie Town stepped down mid 2016 to concentrate on her studies, and the students appointed a new chair, Michael Papanicolaou [Michael.Papanicolaou@student.uts.edu.au](mailto:Michael.Papanicolaou@student.uts.edu.au). New students have joined the committee and more fundraising activities have been planned for 2017, including Cadburys chocolate fundraising sales, a trivia night, and a BBQ.

### SCHOLARSHIP

The Executive Committee of LAM Australia Research Alliance has decided to concentrate current fundraising efforts on creating a PhD scholarship. Ensuring that three years of work can be undertaken, this represents the best value for money we can get.

### PRIZE

In 2017 the "Cure LAM" prize will be rolled out. Open to any student based in Australia, this prize will be awarded to the most innovative approach to Diagnosing / Treating / Curing LAM.

### COMMITTEE

The committee needs help to achieve its objectives. We would like to co-opt additional members. Please get in touch if you would like to be involved.

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### Donations

Our warm thanks to Gabriel Roffey for her \$800 donation to LAM Australia. We recently received a donation in loving memory of the Broomhead twins. Further donations have also been received. All gifts to LAM Australia Research Alliance are tax deductible and greatly appreciated.

At this time of year, we are very grateful to those who choose to donate to our worthy cause rather than to buy Christmas presents. One woman stands out because she decided several years ago that her grandchildren would learn the importance of charity if she became their role model by giving to LAM Australia Research Alliance on their behalf. To donate direct to LAM Australia Research Alliance our account number is 012-055 4926 67193. Be sure to email details to [admin@lamaustralia.org.au](mailto:admin@lamaustralia.org.au) so we can provide a receipt.

### Fundraising through sales of Entertainment Books

Once more the extraordinary Kate Wingrave has raised close to \$1000 through Entertainment Book sales. That's on top of organising a fundraiser with Laura Kolomyjec at her gym, Genesis Fitness – Bentley, which raised \$1100. Kate's fundraising is getting off to a great start in 2017. She's teaming up with Donna Albertini and others to organise an 80s dance party in Bicton. Kate, hopes her energy and enthusiasm will encourage others to help sell Entertainment Books. They make great gifts and LAM Australia gets \$13 from every sale.

### Living with LAM Thesis published

Congratulations to Denise Haylen on the publication of her insightful thesis after years of work. Denise is planning to talk about her findings in Sydney and Melbourne in 2017.

### Be well

Best wishes to world leading LAM physician and researcher, Joel Moss, who is recovering from a stroke. We wish anyone living with LAM who is or has been unwell a very good recovery. Recent pollen incidents in Melbourne and Canberra may have challenged women living with LAM. Whether dealing with pollen, smoke, winter chill, or the high humidity of summer, it's important to take the necessary precautions, which may mean staying indoors or reducing outdoor activity till the air clears.