

April 2015

Greetings from the President

"But you look so well!!" Why is it that people often act disbelieving just because a woman who is living with LAM looks perfectly healthy? Like Kristy Hope, whose story is on the following page. It's true - a diagnosis of LAM isn't etched on one's face. However, it is likely to be etched on one's psyche when difficulty with breathing and long term uncertainty impact on living with this diabolical disease. That's when the sort of therapy that Ros Pollard, who is also living with LAM, can make a big difference to how one lives.



Established in 2006, LAM Australia Research Alliance is now in its tenth year. Let's make this a year when we all do our best boost research funding and increase awareness of lymphangioleiomyomatosis. Warm thanks to Kristy Hope, Pat Evans and Faith Wieland for their assistance with this newsletter.

Please let me know how you are doing and what you are doing to help our cause.

Together we can conquer LAM.

Wishing you well, Janet Neustein, President

Join us in marking Worldwide LAM Awareness Day on 31 May 2015

Rather than a walk in the dark, we hope our walk in the park will shed light on the rare disease we know all too well from the inside: lymphangioleiomyomatosis.

I urge women living with LAM, their families and friends to organise events elsewhere in Australia to mark Worldwide LAM Awareness Day 2015. If you live in Sydney, please join in the walk in Centennial Parklands.

R: LAM T-shirts made a splash at the 2014 walk for Worldwide LAM Awareness Day.



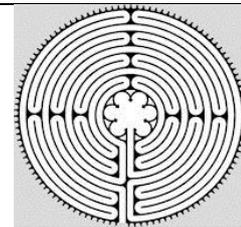
SYDNEY WALK

Linger in the labyrinth, we will discover the therapeutic powers of walking in a special space.

Sunday 31 May
Centennial Parklands.

We will meet at the Learning Centre on Dickens Drive at 9.45 for a 10 am start.

Afterwards we will hear about the therapeutic power of the labyrinth from our Patron, Dr Linda Friedland.



To register go to <http://lamaustralia.org.au/worldwide-lam-awareness-day/>

To donate go to <https://give.everydayhero.com/au/worldwide-lam-awareness-day-2015>

Invitation to attend the LAM Australia Research Alliance Annual General Meeting 2015

Monday 01 June 2015 at 5.30 pm @ the LAM Australia office, level 4, 209 Oxford Street, Bondi Junction
After the meeting, join us in toasting Worldwide LAM Awareness Day.

All positions on the Executive and Committee are open for nominations.

We welcome enthusiastic new committee members. Bring your expertise to LAM Australia and help us grow! To RSVP and/or ask any questions, please email us at admin@lamaustralia.org.au

The LAM office is located above Kathmandu with lift access from the foyer at 209 Oxford Street. Two hours' free parking available in nearby Westfield. The office is just a block from Bondi Junction Bus/Rail Interchange.

Kristy Hope's LAM journey



I want to thank the men and women (scientists, doctors and my sisters who are living with LAM) for the hard work and effort, stress and discomfort that are part and parcel of trying to find a treatment/cure for LAM. Although we don't yet have a cure, we have a drug which is slowing down the progress of LAM in some cases.

My name is Kristy, I am 35, and I've been diagnosed with LAM since August 2006. I had been having symptoms which I suspect were LAM related since 2000 – that's 15 years now! I've been having lung collapses since May 2009. For me it wasn't the 'odd' collapse here and there ... I had a secondary 'curse' of being a woman... Every time my hormone levels changed, my lungs would collapse. Eventually I came to terms with the fact there was no magic cure in hormone adjustments, diet, or wishful thinking. I agreed to give a 'trial' drug, everolimus, a try. It took over six months to work, but after three years in which my lungs collapsed more often than they were inflated, they finally stopped collapsing.

After two years on this miracle drug, I was badly affected with the flu, so had to stop taking the drug till I had got over the flu. That's because everolimus is an immune suppressor. Stopping it while I recovered from the flu was the best course of action. I'd been wondering if the drug was actually still working, or if it was having a placebo effect. Fast forward seven weeks; I was 'healthy' again so started back on my medication. Two weeks later (I suspect this is how long it took for the drug to fully leave my system), both my lungs collapsed. Question answered. I have continued taking my medication and luckily have experienced no more instances of pneumothorax. My doubts have subsided, my lung function has stabilised, my lymphatic tumour is stable (previously it had been growing up to 3cm/year), and I'm having lots of fun with daughter, Alegra..

Without funding/fundraising ... that is, without your help and the help of the many people who put in the hard yards to search high and low for a cure, we wouldn't have drugs to treat LAM. I am very grateful to everyone who has had a part in bringing this to us. However, the search doesn't and cannot stop here. LAM is a debilitating and fatal disease which needs a cure.

Please help us. One day it could be your daughter, your sister, your mother, your wife or your best friend who is diagnosed. Donations are tax deductible, and every dollar brings us one step closer to developing effective treatments and a cure for LAM.

EVENTS AROUND AUSTRALIA in 2015

Adelaide SA: Michaela Dodimead, sister of a woman newly-diagnosed with LAM, is organising a team for the Sunday Mail City Bay Fun Run on Sunday 20 September. Participants will be running and walking to increase awareness of LAM and raise funds for research. For further information, email admin@lamaustralia.org.au

Brisbane QLD: *LIVING WITH LAM CAN BE TOUGH AT TIMES*

Did you read Gai Golder's story in *The Australian Women's Weekly* on line? Check it out at <http://www.aww.com.au/family/relationships/2015/2/real-life-read-when-my-mum-was-given-five-years-to-live> ... it will be up on our website very soon.

Melbourne VIC: Donations in memory of Esther Hristodoulakis, beloved mother of Anna Lakic provided over \$4000 for LAM research.

Ros Pollard represented LAM Australia at the Rare Disease Summit in Melbourne 27-28 March. The summit was convened to develop a National Plan for Rare Diseases - *Driving Collaboration, Driving Action*.

Yasuko Wilson raised \$800 for LAM research by selling some of her oil paintings, which are displayed in a café gallery.



Perth WA: Patron, Linda Friedland attended a Rare Voices Australia Round Table which informed the Summit.

Sydney NSW: Donations in lieu of gifts in celebration of Miri Sonnabend's 40th birthday (8 years post diagnosis) raised over \$5000 for LAM research.

Janet Neustein attended a Rare Voices Australia Round Table which informed the Melbourne Summit.

LAM overseas: LAMposium 2015 Chicago Illinois, 26-29 March

LAM Australia Research Alliance was not represented this year. However two members of the NZ LAM Trust, Director Bronwyn Gray and Trustee, Jen Shieff (first cousin of Janet Neustein) attended along with 130 women living with LAM, their partners, scientists, clinicians and the LAM Foundation team.

You can read Jen's report on the NZ LAM Trust site www.lam.nz.org She asks if we are any closer than we were a year ago to finding a cure? And answers, "Yes, I believe so. There might be an even better combination than rapamycin (sirolimus) and simvastatin, which is having a remarkably good effect on many women with LAM. Also, there may be answers in looking more closely at lipid metabolism, at the way proteases behave, at the RNA miR21, at auto-immune therapeutics, and even at Resveratrol. A LAM cell line factory is being piloted to enable researchers to see exactly what happens when certain therapies are applied."

LAM Australia database now lists 104 women

If you know of anyone living with LAM who has not registered with us, please encourage her to do so. We also encourage everyone to join LAM Australia – there is strength in numbers. Download the membership form from www.lamaustralia.org.au

Supporting women living with LAM is a major aim of our organisation. A crucial time for support is when a woman is newly diagnosed or facing a health crisis. Through personal contacts and our website, we aim to reach out to all women living with LAM at any stage of their journey. If we can help you or someone you know, email admin@lamaustralia.org.au or call 02 9387 1899. Likewise, if you have time to support other women living with LAM by lending a listening ear, please let us know and we may be able to put you in touch with others who would appreciate speaking to someone who is also living with LAM.

Ros Pollard has trained in holistic counselling for her art therapy certification and in Compassion and Presence in Contemplative Care with Nursing Australia. She can be contacted for support on 0414 600 299 or rpollardiso@yahoo.com.au If you're living in Melbourne, you might want to experience art therapy with Ros.

Ocean Jasper Art Therapy Ros Pollard Qualified Art Therapist www.oceanjasperarttherapy.com

Freely explore, discover and unravel the essence of who you are through art processes which nurture healing, wellness and transformation. Ocean Jasper Art Therapy provides a safe and caring environment and professional patient support for individuals with health related conditions. Ros Pollard offers one-on-one sessions for adults and children. Artistic ability is irrelevant yet the benefits are many - alleviating the stresses and anxieties of daily life and concerns for the future. Art therapy provides an outlet for feelings and helps people let go of what no longer serves them by developing new perspectives on life.

Research update

Research is the key to developing effective treatments for women who don't respond to current remedies, and to discovering a cure for LAM. Women living with LAM are our daughters, partners, mothers, grandmothers, sisters, cousins and friends. Let's do what we can by funding research to remove the impact of the disease from the lives of women living with LAM.

Under the guidance of Dr Brian Oliver, research into LAM is continuing at the Woolcock Institute of Medical Research. Fahad Shaikh, an enthusiastic Honours student is researching biomarkers in the LAM laboratory.

How you can help research

- 1 by providing samples - If you are having a procedure which will yield a sample (chyle, tissue, or blood), please contact Brian Oliver, ideally with two weeks' notice; that is, if you have advance notice yourself! Brian will arrange the ethical approval and transport to the Woolcock Institute. Brian Oliver T +61 (0) 401 142 571 / brian.oliver@uts.edu.au
- 2 by fundraising
 - ✓ create your own page on the LAM Awareness Day Everyday Hero website. <https://give.everydayhero.com/au/worldwide-lam-awareness-day-2015>
Each photo and story of a LAM community member increases our chances of attracting substantial funding for research. It's easy, effective and makes you part of the worldwide LAM research effort.
 - ✓ bring your own creativity to LAM fundraising by organising your own fund raising event. We have been blown away by the amazing LAM research fundraising projects you have run. You might like to organise a walk and fundraiser in your area for Worldwide LAM Awareness Day, a film night, a picnic, Entertainment Book sales, a swimathon, an exhibition of artwork, a trivia night or a raffle. We love hearing and sharing what you have done. Every dollar you raise will help fund LAM research.

