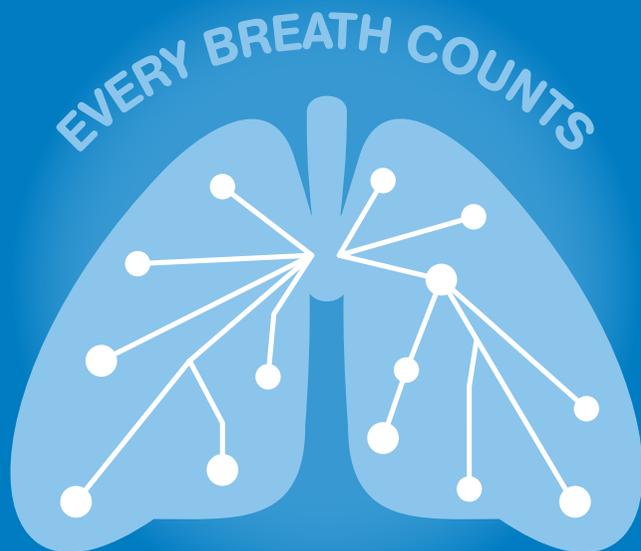


# Lymphangiomyomatosis LAM



Help us fund  
a cure for LAM



**LAM AUSTRALIA**  
Research Alliance  
SEEKING A CURE FOR LAM  
LYMPHANGIOLEIOMYOMATOSIS

## What is LAM?

**LAM is the short form of lymphangiomyomatosis**  
(lim-fan-gee-o-ly-o-my-o-mat-o-sis)

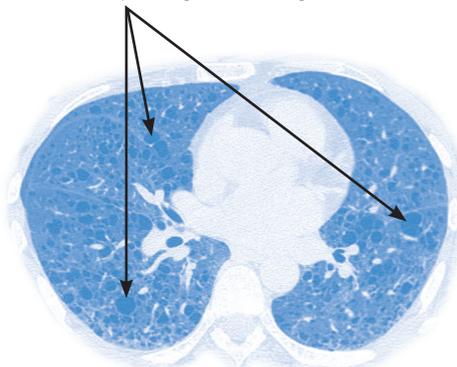
**LAM is a rare cystic lung disease unique to women. It can be inherited along with tuberous sclerosis, or can result from a random genetic mutation.**

**LAM is devastating.** Sporadic LAM is unexpected, unpredictable and irreversible. Although women living with LAM usually look healthy, they struggle with declining lung function and other symptoms of varying type and severity. LAM typically strikes women in their 30s, making pregnancy inadvisable and life expectancy uncertain.

**LAM is progressive.** Acting like a cancer, mutant cells thought to originate in the uterus, metastasise to the lungs and other organs via the lymphatics. Air-filled cysts proliferate in the lungs. Smooth muscle cells replace the lining of the lungs. As breathing becomes increasingly difficult, some patients may become dependent on supplementary oxygen. Cysts and growths may develop in the kidneys and abdomen too. The rate and degree of progression vary.

**There is no cure... yet.** An effective, purpose-built LAM drug has yet to be developed. Following a comprehensive international trial of rapamycin, specialists have been prescribing versions of this drug with increasing confidence. Although in some cases the medication slows the disease process, it cannot stop it. Nor can it repair damage already inflicted. In severe cases a double lung transplant is the only option. That is why developing a cure is vital.

*High-resolution CT scan shows bilateral lung cysts (arrowed) distributed randomly throughout the lungs.*



## Help us fund a cure for LAM

**We need your help to develop effective treatments and a cure for LAM.**

**An irreversible lung disease, LAM usually strikes healthy women in their child-bearing years.**

Women like Tania, Marion, Anna, Mel, Kate and Yasuko struggle with the effects of LAM every day. The prospect of a cure gives them hope. In the past decade scientists and clinicians have made huge strides in understanding and treating LAM. With government funding hard to come by, further research depends on financial assistance from the private sector - chiefly, individuals like you.

**Research gives hope to women living with LAM.**

The primary goal of LAM Australia Research Alliance is to raise funds for urgent research into LAM. A not-for-profit organisation, LAM Australia is run entirely by volunteers. We have raised over \$500,000 for LAM research to date. Most funding has been directed to the Woolcock Institute of Medical Research at the University of Sydney. Scientists at the Woolcock had a breakthrough of international significance when they identified lamstatin, a protein missing from the lung tissue of LAM patients.

Now working to isolate LAM biomarkers, Woolcock scientists hope to develop a simple blood test for diagnosing and monitoring LAM. Further research is tracking the disease pathways of LAM, leading us closer to finding effective treatments. Scientific discoveries relating to LAM are also likely to contribute to our understanding of other diseases, including cancer.

**Knowledge is essential to treatment and diagnosis.**

Because it resembles other lung complaints, LAM is often misdiagnosed - sometimes for years. It is vital to increase awareness and understanding of LAM in the medical profession.

**Affirmative action counters helplessness.**

Living with a disease which is progressive and unpredictable is challenging physically and psychologically. LAM impacts on the women living with the disease and their loved ones. Alleviating the isolation of this rare and debilitating disease, we provide a support network and encourage women to be involved.

**Together we can conquer LAM**

## Living with LAM

### •• Tania

*"I am hopeful my life will improve."*



Late in December 2014 I was hospitalised with terrible pain. A scan revealed abdominal bleeding and abnormalities in my lungs. A biopsy confirmed LAM. Post biopsy I developed pneumonia, a pulmonary embolism and a pneumothorax. Discharged for Xmas after six days in intensive care, I was readmitted that same evening with further internal bleeding. I turned 44, but my birthday passed in a blur. Now a little better, I am working one day a week and hope that being on rapamune will mean I can work more often.

I rely on oxygen 18-20 hours a day. A few years ago I had noticed I became breathless upon exertion, but had put that down to being unfit. Although I kept exercising, I wasn't getting fitter. Now I know why. Trying to be positive, I hope that with treatment, time, and the support of family and friends, my life will improve.

While having radiation for breast cancer in 2010, I started coughing and was increasingly breathless. When a test revealed airway obstruction, I was referred to a respiratory specialist. Identifying LAM from my CT scan, he sent me to a LAM specialist. The cancer treatment had been gruelling, but I thought I'd cope better than I did with the LAM diagnosis. However, I was just as devastated - crying uncontrollably, reluctant to face anyone, disinterested in food, and burdened by everyday tasks. Slowly, I crawled out of the gloom by keeping things simple and finding beauty in the world and people around me.

### •• Marion

*"LAM chose me. I have to make the best of my life."*



### •• Anna

*"How could a woman who lived a healthy life and never smoked be afflicted by this?"*



It was 2001 and I was 37, breathless, and coughing up blood. A scan revealed I had LAM. I was told there was no cure and I had one to 10 years to live. I'd wanted a baby, but pregnancy was now too risky. Fast forward to 2015: very short of breath, I can't walk 10 metres without a break. Relying on oxygen on bad days, I dread a heart attack if I do anything active. In 2009 I was prescribed rapamycin to shrink the LAM-related tumours in my abdomen and bowel. The drug also stopped my gurgling and coughing up phlegm and blood. I try to make the most of each day.

### •• Mel



*"I do spin classes - how can I have LAM!"*

I was 40 when a lung collapsed and I was diagnosed with LAM. It was March 2013. A pleurodesis ensured no repeat collapse. Now ok physically, I have scars and tenderness inside and out from the surgery. Still, I work out, keep fit and work harder than ever. The chief impact of my diagnosis is uncertainty about my future. I live in fear of a check up which shows my lung function is deteriorating. What if my daughter has to grow up with a sick mother? The upside is that I live in the moment much more now than pre diagnosis. Knowing I have an incurable, fatal disease certainly puts life in perspective. This is why I got involved with the LAM group - to do something constructive.

Following excruciating back pain, I was diagnosed with severe LAM in 2010. I was 39 and my children were three months and 20 months. I had been breathless for a year, but told I was just anxious. In 2010 the only treatment/"cure" was a double lung transplant. Now on rapamune and supplementary oxygen, I am fairly stable. LAM Australia, a wonderful support group, has given me the courage to be strong and to live for the present. I'm lucky to have a loving family and friends. I work part-time, make the most of each day, enjoy my children and focus on what is important.

### •• Kate



*"Each day is hard for me and I worry what the future holds. Will I see my children grow up?"*

### •• Yasuko



*"Every day I breathe out negative air and breathe in hope."*

Despite being slim and very fit, in 1999 I became so breathless, I needed supplementary oxygen daily. I was diagnosed with LAM and hospitalised repeatedly with flu and pneumonia. In 2012, I relocated to Melbourne due to a family tragedy, but became so ill, I was admitted to intensive care. My LAM specialist prescribed rapamycin and a statin. Still on home oxygen, I am listed for a double lung transplant. I keep hoping for a breakthrough to cure my rare disease. My enjoyment of life centres on my wonderful daughter and grandson and my love of painting.

## Donate now

The more money we raise, the more research we can fund. With government funding limited, research depends on private support. By making your **fully tax deductible** contribution to the LAM Australia Research Alliance, you will ensure the research momentum continues.

**Every donation large or small gives hope to women who are living with LAM and hoping for a cure.**

**You can donate to LAM research in Australia by:**

1. Making a payment directly into our ANZ account:  
LAM Australia Research Alliance  
012-055 4926 67193
2. Mailing a cheque to:  
LAM Australia Research Alliance  
PO Box 636, Bondi Junction NSW 1355  
Australia
3. Visiting [www.lamaustralia.org.au](http://www.lamaustralia.org.au) for links to everyday hero and GiveEasy

**If you have any questions, please telephone our office on +61 2 9387 1899.**

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Find out more about women living with LAM at [www.lamaustralia.org.au](http://www.lamaustralia.org.au)