



For Lyme Disease Awareness & Action

LYME DISEASE  
ASSOCIATION OF AUSTRALIA  
ABN 46 417 706 647

25 July 2016

MEDIA RELEASE

## Lives lost to Lyme-like illness remembered on Red Shoe Day – July 25<sup>th</sup>

Lives lost to Lyme-like illness and other illnesses that are invisible to the health system are remembered around the world on Red Shoe Day – 25th July 2016. Patients suffering from these diseases routinely feel invisible as they are left to fend for themselves by a health system that does not recognise nor understand their disease. A lack of investment in research is widely misunderstood to be an absence of evidence. In this world of evidence based policy it has been a death sentence for some.

Families and friends come together on Red Shoe Day to speak the names of those they have lost. “The day is not only to remember those that have passed, it is also to celebrate their lives, and to share the wonderful memories their time on this earth gave us,” said Karen Smith, Australian based co-founder of GLiIO.

Theda Myint, the Lyme-like patient who took her own life three years ago and whose battle for recognition has inspired this annual event is remembered fondly by many. Her mother Carol Adams said Theda wanted the public to know about this illness. ‘To bring it out in the open, how it destroyed lives and that those with it were treated very badly by the medical profession and by our government.’

Theda is one of over twenty in the past 5 years who’ve lost their lives to Lyme-like illness. Many more could be misdiagnosed. The Lyme-like community gathers in much needed hope that things will change. They also share a desperate need for medical treatment. With the right research their many symptoms may yet be proven to be caused by bacteria or viruses that haven’t even been named yet in Australia.

An open heart and clear mind is needed to address this neglected public health crisis. The patients and handful of compassionate treating doctors are the evidence that justifies action. LDAA is calling for the 45th Parliament to immediately reinstate the Senate Inquiry into the ‘Growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients.’ Over a thousand patients across the nation submitted evidence of suffering, of lives ruined and taken by this debilitating disease.

Enough lives have already been ruined or lost. With the right policy and funding Australia can catch up to the rest of the world and start to treat patients who are sick with Lyme-like illness with compassion, respect and world’s best practice treatment.

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Media contact: [media@lymedisease.org.au](mailto:media@lymedisease.org.au) or 0406 378 792

Photo library: <https://www.facebook.com/LymeDiseaseAustralia/photos>

For more information about Global Lyme and Invisible Illness Organisation (GLiIO) please visit: <http://www.globallymeinvisibleillness.org/>

Additional resources for media are available from the Lyme Disease Association of Australia’s [website www.lymedisease.org.au/media](http://www.lymedisease.org.au/media)

Senate Inquiry page: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Lyme-like\\_Illness](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lyme-like_Illness)

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PO Box 137, Stockton NSW 2295  
[info@lymedisease.org.au](mailto:info@lymedisease.org.au) | [www.lymedisease.org.au](http://www.lymedisease.org.au)