

## FOREWORD

I AM THE WOMAN WHO WOULDN'T DIE. IN FACT I DIDN'T GET an invitation to my 25-year high school reunion because the organising committee had heard that I had passed away several years ago. Instead I had spent many years chronically ill. For eight years I was unable to wash or dress myself, often unable to feed myself, had trouble swallowing and was either stuck in bed, in my electric wheelchair, or if I was having a REALLY good day and was exceptionally determined, used a walking stick. Today, following correct treatment for Lyme disease I drive, have returned to work part time, wash, dress and feed myself, and am learning to ride a unicycle - I'm not very good at it, but I'm giving it a go and having fun doing it.

In 1987 my life changed forever. I was a fit, very healthy, exceptionally active 18-year old. I had been chosen among hundreds of applicants to go to Japan as a Rotary Exchange Student for a year, and I was having a ball. I threw myself into learning new things and having new experiences, including going on my school's Shugaku Ryoko (a trip for senior students to explore another city). We planned it for months, and one of the things that I looked forward to was patting the deer in Nara. I spent a long time playing with the cute deer, feeding them and patting them. It was only many hours later that I discovered a tick on my neck in the hairline, so I got a friend to pull it out (without tweezers, which I now know led to me getting Lyme disease and Babesiosis, but I didn't know correct tick bite

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first aid back then). A few days later I had an embarrassing red rash on my neck that looked like ringworm, so I pulled my long hair down to cover it and waited for it to go away. Little did I know how much that tick bite would change the course of my life, and that of the people that I love.

According to the surveys done by the Lyme Disease Association of Australia (and mirrored in research in the US & Europe) only 30% of people with Lyme disease remember a tick bite – this is because the tick injects you with a local anaesthetic so that it can be attached for longer. I didn't get suddenly seriously sick after my tick bite – I slowly got sicker and sicker until I could no longer function. Initially I came down with chronic fatigue syndrome-like symptoms, and that was what I was diagnosed with. More symptoms appeared over the years and as they did, I started to collect new (incorrect) diagnoses – severe irritable bowel syndrome (I spent years unable to leave my house unless I knew exactly where the toilets were along my route and at my destination, and at my worst I was also bowel incontinent and haemorrhaging from the bowel) which then was changed into inflammatory bowel disease when the pathology came back with inflammation in my bowel, gastroparesis (because my stomach wouldn't empty), trouble swallowing (I had a reconstruction of part of my oesophagus to try and fix this, but spent many years on liquid food as it was what was easiest to swallow – I still have an aversion to soup and smoothies), fibromyalgia (because I had severe muscle and nerve pain) which changed into reflex sympathetic neuropathy, sero-negative lupus, and finally when I was unable to dress, wash or feed myself anymore the doctors started exploring Motor Neurone Disease (MND) as a diagnosis.

I refused to even go and see a specialist about MND as a potential diagnosis because I knew it was a death sentence, and so my very kind local General Practitioner (GP) did some research with me – as soon as we found Lyme disease we knew that was what I had. Along the way there had been many mad dashes to the hospital, and if I ever hear the phrase “Oh, we've never seen that before” I will scream. Ironically I discovered later that I was one of the lucky ones – I remember my tick

bite and had the classic EM rash that only 30% of Lyme patients get. In 2005, despite the fact that my blood test was negative<sup>1</sup>, I was clinically diagnosed with Lyme disease (my Babesiosis diagnosis would follow a few years later) by a Professor of Immunology in Sydney. Unfortunately he was unable to treat me, and my GP and I were left to work it out for ourselves.

My treatment followed the Burrascano guidelines for treating Lyme disease (included as an Appendix in this book), and though the treatment prevented me from dying, without the guidance of an experienced medical practitioner to help us (and diagnose my Babesiosis co-infection), it didn't make me well. In 2009 I was lucky enough to meet Dr. Nicola McFadzean and she began treating me. Having someone who knew the nuances of Lyme disease treatment take on my care made a massive difference and within two years I was able to return to work, dress, wash and feed myself, and start on trying to ride that unicycle. Dr. McFadzean gave me my life back.

Unfortunately I passed on my Lyme disease and Babesiosis to my beautiful twin daughters through the placenta before they were born – it mildly affected one daughter, but severely affected the other. She was unlucky enough to be bitten by a tick on a camp in Sydney, and this extra exposure to the bacteria that cause Lyme disease overwhelmed her body. She has been in a wheelchair for the past 2½ years. At one point she was completely paralysed, unable to swallow and had trouble breathing, but because she had Lyme disease, doctors in our local hospital refused to treat her. In fact, at her worst, they handed her over to us, and told us to bring her back when she stopped breathing.

Many well-meaning, very good doctors have treated my family and me over the years, and have tried desperately to make me well. For that I am incredibly grateful, but their ignorance of Lyme disease ultimately led to

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1 My Australian blood tests were negative, but my blood was sent to the USA in 2009 and I returned a weak positive test.

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the loss of my ability to swallow, walk, use my arms, drive, wash or dress myself, and at 33 I had to medically retire. It is not the fault of the doctors at all. They only know what our health department tells them – and most of the health departments in Australia continue to push the myth that there is no Lyme disease in Australia (despite the large amount of evidence to the contrary) - and so doctors are not aware of it as a potential diagnosis. Even people like me who acquire Lyme disease overseas are unable to access adequate treatment. This leads to thousands of people suffering the way that I did, and has led to the death of some (for example Karl McManus who died from Lyme disease in 2010). No other disease in Australia has patients treated with such contempt – if I acquired leprosy or HIV overseas I would be able to access treatment back in Australia, but because I came back from my year in Japan with Lyme disease I have been largely unable to access treatment in Australia – which is why this book by Dr. McFadzean is so ground breaking, as it will allow local doctors to treat Lyme disease patients with confidence. Dr. McFadzean has treated close to one thousand patients with Lyme disease and many of them have been able to return to their old lives following years of disabling symptoms of undiagnosed Lyme disease and associated co-infections. Many of us owe our lives to Dr. McFadzean, and for that we are all incredibly grateful.

Currently I am the President of the Lyme Disease Association of Australia (LDAA). The Lyme Disease Association of Australia works to provide information and support to people who have Lyme disease (or suspect they have Lyme disease). The LDAA also lobbies the government, businesses and community groups on behalf of people with Lyme disease to change public health policy around Lyme disease in Australia and to work towards ending discrimination for people suffering from Lyme disease (this is a very loooooooooooooooooooooong process). I took over the presidency of the LDAA in 2010, which was founded in 2009 by Dr. Mualla McManus (who now runs the Karl McManus Foundation). The LDAA draws on the work of the Tick Advisory Group in Sydney (TAGS) in the 1990's, whose tireless work in Lyme disease and tick education saved many lives.

I tell you my story, not because I am anything special, in fact my story is reflected in the story of the thousands of people who contact the Lyme Disease Association of Australia every year for help. I tell you my story to let you know that there is hope. With correct treatment, people who have been suffering for decades with a “mystery illness” that is in fact Lyme disease and its associated co-infections, can get well and return to doing the things that they love with the people whom they love.

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