

My Story

- Name: [REDACTED]
- Age: [REDACTED]
- My address is: [REDACTED]
- My postal address is: same as above
- You can contact me on: [REDACTED]
- I want my story to be public

About my journey

I'm an Australian citizen, originally from Bucaramanga, Colombia. I live in Australia since 2008. I used to be a very active person, running 7km twice a week. I was a very outdoorsy person; bush walking and trekking were among my favourite activities.

On the 23 of October 2012, after two days of feeling unwell with fever and joint pain, I experienced an anaphylactic shock with severe seizures. When the paramedics arrived they stabilized me, an ambulance transferred me to [REDACTED] Hospital, in Kogarah, NSW.

I spent 7 days at the hospital with frequent seizures, headaches, fevers, sweats, weakness, and many other typical symptoms of a bacterial infection. In the discharged report, references to my mental health ("*elements of somatisation*" "*panic attacks*" and "*anxious*"), were used loosely and subjectively to justify and downplay the overwhelming clinical evidence (such as lymphadenopathy, joint pain, headaches, massive drop in neutrophils), that linked my symptoms with a classic acute bacterial infection.

The immunologist, who signed the discharge report on the 30 October 2012 misdiagnosed me with an extremely rare condition that he named "*Post viral arthralgia, myalgia and fatigue*" an illness with unknown aetiology and unclear criteria for diagnosis and treatment. The final recommendation on this record reads: "*No follow up with Infectious Diseases, Rheumatology or Psychiatry is required*"

After leaving the hospital my health deteriorated rapidly. I lost 20% of my body mass, lost my job and spent the next 14 months most of the time bed ridden. During my first year of illness, I visit more than 35 doctors and specialists

(neurologists, immunologists, rheumatologists, gastroenterologists, etc). I spent all my savings trying to to treat my *“Post viral arthralgia, myalgia and fatigue”*. Every specialist I saw acknowledged that something was wrong with my health, but could not explained the root that caused of my illness, the results at the end of each consultation was always the same, yo have Chronic Fatigue Syndrome, I can’t do anything.

In January 2014, reading about Lyme disease in medical journals, I search for a Lyme Disease Meidcal Doctor in Australia. He diagnosed with neuroborreliosis, bartonellosis and babesiosis (test results from 2 independent laboratories Armin Labs located in Germany and Australian Biologics located in Australia have been attached to this submission) I started treatment for Lyme disease immediately.

I never experienced the bulls-eye rash associated with a tick bite. However, after one year of oral antibiotic treatment, a rash appeared on my right leg. (photographic evidence upon request) The rash waxes and wanes becoming red and hot for hours and some times days, this consistent pattern has been followed for more than 18 months (photographic evidence available upon request), and is a clear, and painful evidence that I was bitten by an infected tick.

To this day, (3 years and 4 moths after the tick bite) I have visited more than 45 doctors. Every time that the words “Lyme disease” are mentioned, the doctors are reluctant to order any procedure. They just say “it is too complex”, “it is a political issue” or “I’ll give you the referral to another doctor”. I do not have any support from Centrelink, every expenditure for my treatment has to be covered by myself.

Neurological symptoms, including difficulty in concentrating, muscle weakness, and twitches, have progressed over the time that I’ve been fighting against this debilitating illness. I cannot shake the thought that this painful journey could have been prevented with prompt diagnosis and timely intervention at the hospital.

In July 2015 I had a cardiac arrest. Further investigation led to a stent being inserted in one of my coronary arteries. Heart diseases at 39 years old are certainly a very unusual event in healthy patients, but a far too common event with patients with untreated Lyme disease.

Two weeks ago I started my intravenous antibiotics treatment. The authorisation for the insertion of the PICC line took more than 13 months to obtain, it was granted 2 years after my diagnosis and more than 3 years after the admission to the hospital. It was difficult to obtain because Lyme Literate Medical Doctors are afraid of losing their licenses or facing disciplinary actions for helping patients like me.

No doctor has dispute the Lyme diagnosis (there is no way you can dispute evidence from 2 independent labs), but no GP is willing to treat me or help me. The only words that I can find to appropriately describe the behaviour from doctors and specialist towards this life threatening infection is “rampant negligence”.

Prior to my tick bite I used to run 7-10 Km per week, enjoyed a productive and healthy lifestyle with an active social life. Due to the lack of energy and a reckless misdiagnosed I’ve lost my career, my longevity, my health, many friends and even members of my family.

Australia, would never know how many people is affected if the diagnosis criteria and attitude towards this disease doesn’t change. This is the moment to change that and recognize this public health issue that is affecting our country.

Documents Attached:

1. LGM HospitalDischarge Oct2012.pdf
2. LGM AustralianBiologics test results.pdf
3. LGM ArminLabs test results.pdf