

## My Story

- Name: Ingeborg Kuiper
- Age: [REDACTED]
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- You can contact me on: [REDACTED]
- I want my story to be public.

## About my journey

I acquired Lyme-like illness at home, in [REDACTED] QLD. It started when I hugged my dog. Hours later, I was scratching at an itch in my neck. When I looked closer, I noticed it was a small tick. I started to get sick several days later.

I was born in the Netherlands (ie outside of Australia) and had also travelled to Europe about 8 months before getting sick. While this means my case of Lyme disease is difficult to prove as being acquired in Australia, it is extremely unlikely that I acquired Lyme while in Europe. This is because I had been living in Australia for 15 years with no health problems and the recent trip to Europe was in the middle of winter, when ticks are inactive. Also, I am not aware of having been bitten by any ticks while in Europe, while I know I was bitten by a tick in Australia a few weeks before getting sick.

Type of Bite: tick bite.

I was relatively lucky, because I was able to get an accurate diagnosis within months of getting sick. This was as a result of sending blood samples overseas. I have since met many people with Lyme who took years to find out why they were sick; and these people tend to take a very long time to recover, even with effective treatment from overseas.

I have positive blood tests from Infectolab, Germany. I tested positive for *Borrelia burgdorferi*, as well as a number of other related conditions:

- Immune-suppression:
  - Low Natural Killer Cells (3, compared to reference of 6 – 29),
  - Low CD-57 positive NK-Cells, both Heparin (0, compared to reference 2 – 77) and absolute Heparin (11, compared to reference 130 – 360).

Comments: "The CD57-cell-count indicates a chronic immune-suppressive situation which may be caused by *Borrelia burgdorferi*"

- *Anaplasma phagocytophilum*. Comments:
  - Antibodies: "Anaplasma-IgM borderline antibodies detected, indicating an infection. Please send a control in 4-6 weeks".
  - Elispot: "The Elispot indicates cellular activity against *Ehrlichia*."
- *Chlamydia pneumoniae*. Both the ELISA and Elispot were positive. Comment: "The detection of specific *Chlamydia pneumoniae* –IgA-antibodies indicates an infection. Please consider the result of the *Chlamydia pneumoniae*-Elispot".
- *Mycoplasma pneumoniae*: Positive for IgA, and negative for IgG and IgM.
- Epstein-Barr-Virus: Positive for lytic (12, compared to reference of <2) and latent (34, compared to reference of <2). Comment: "The Elispot-Lymphocyte Transformation Test (LTT) indicates cellular activity against Epstein-Barr-Virus."

Before finally getting a useful diagnosis, I had seen at least 10 doctors and medical practitioners in my journey and have been admitted to hospital 4 times for my illness. Unfortunately, as almost all Australian test results were negative, some hospital doctors started to come to the frustrating conclusion that my problems were psychological.

Due to Australia's stance on Lyme I had to struggle to get an accurate diagnosis, and then again to get treatment. Despite having Medicare and private health insurance, I had to fund all diagnosis and treatment myself, including the overseas testing, flights, accommodation, treatment in Europe, and all medications.

## My life

Prior to my illness, I lived a happy and healthy life. I have always maintained close to my ideal weight and have been very healthy. My husband and I have been foster parents for 18 years, and have fostered around 60 children in that time. My husband and I own a successful business that employs 55 staff. This illness came completely unexpectedly.

Suddenly, within a matter of weeks, I was a patient with a "mystery" illness that no doctor could diagnose. I suffered continual pain throughout my body: pain that would move and come and go. My arms felt like they

weighed 20 kg each. My heart would unexpectedly lose its rhythm, and skip beats. I was suddenly unable to climb a single flight of stairs without having to stop half-way and wait for my heart to get back to normal and my breath to come back. At first I was taken seriously. During a series of hospital admissions, several Doctors made serious and genuine attempts to find out what was wrong with me. However, after a seemingly never-ending series of negative test results, some doctors started to wonder whether the problem was psychological. There are no words that accurately describe how frustrating this is.

We eventually found a "Lyme aware" doctor. This doctor (who we cannot name) was suspicious at how we found him/her, because he/she needs to keep his/her willingness to diagnose and treat Lyme a secret, due to the Australian medical authority's tendency to punish any doctor who treats Lyme. This doctor helped us organise testing for Lyme in the USA. In order to collect blood, we had to be very careful about what we said to the pathology collection staff. If we were to mention it was to test for Lyme, they would refuse to collect the blood. Having to work "under the radar" of the "authorities" reminded my husband and me of the stories our parents told us about living in Europe during the Nazi occupation. This was particularly ironic, given that I was eventually successfully treated in Germany.

The test results from the US indicated Lyme, but were technically inconclusive. However, when viewed together with the pattern of symptoms, our "Lyme-aware doctor" was convinced that the problem was Lyme. On the strength of this diagnosis, we booked into the Borreliosis Centrum Augsburg (BCA) in Augsburg, Germany. The first thing BCA did was more blood tests, using German test technology. These results (summarised above) were conclusive: I clearly had Lyme, as well as a number of co-infections. The treatment program involved a number of weeks at BCA, in order to establish a routine that I would continue at home for approximately 1 to 3 years, depending on how I respond to the treatment. This was a little over one year ago. I have since made enormous improvements. I am able to function again. I have been able to resume my fostering and have taken in a number of children since getting better. The symptoms still come and go, but do so much less frequently, and much less intensely, and are getting less as time goes on.

As mentioned at the start of this submission, I have been very lucky: my husband and I had the determination and resources to press on and get an accurate diagnosis, despite the Australian medical community's hindrance. We had the ability to go to Germany to get treatment, at short notice. Others have not been so lucky. At the clinic in Germany, one of the many Lyme patients we met was a beautiful young woman in a wheelchair. She was from Melbourne. She had suffered from this mystery illness for 10 years and eventually became wheelchair-bound before she finally got a diagnosis of Lyme. By the time she started getting the

treatment she needed, the disease was so far advanced, that it is much harder to treat. We have kept in contact with her. She is also making progress, but her road to recovery is much longer and tougher than mine. When we met each other at the clinic in Germany, we sarcastically said to each other "I thought Lyme isn't supposed to exist in Australia".

It is only a matter of time before Australia wakes up, and accepts Lyme. When this finally happens, some doctors will have good reason to be ashamed of themselves, while others can be satisfied that they at least kept an open mind.