My Story

- Amanda Bramwell
- 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 acquired Lyme-like illness at: unknown.

- I have left Australia. I travelled overseas to the USA, the UK, Germany, France, Switzerland and Hong Kong in 1984 – at the age of 8.

- Type of Bite: unknown

- I have been sick for most of my life. However, if I take that I got sick as a result of my overseas travel, I was sick for at approximately 28 years before I was diagnosed in 2012.

- I have positive blood tests from Igenex in the US, in both IgG and IgM westernblot. I tested positive for B Burgdorferi and Human Granulocytic Ehrlichiosis (HGE) or also known as Anaplasma. I have been clinically diagnosed with Babesia and Bartonella. Additionally, I have had exposure to CMV/HHV-6/Epstein Barr/ C. Pneumoniae.

- I truly cannot count the number of doctors I have seen over the past 30+ years with various ailments that can be attributed to Lyme-like illness. I would have to put it at well over 60+ medical practitioners.
- I have not been admitted to hospital for my illness. However have been admitted for other conditions / ailments which could be a result of a Lyme-like disease.
  - I have been hospitalised with a stillbirth of twin boys (28 weeks gestation) at the age of 19, in 1995.
    - This led to major complications, with a blood clot on my lungs and pneumonia, I was in ICU for approx. a month.
  - I have had major spinal surgery at L5/S1 with a double discectomy and laminectomy, age 30, 2005. I was in hospital for 3 weeks, then a rehabilitation centre for another 6 weeks while I learnt to walk again.

- I have also been diagnosed and suffered from a range of virus's / illnesses including hyperhidrosis and multiple rashes (as an infant), "untreatable" dermatitis, recurrent chronic sinusitis, chronic bronchitis, pharyngitis, pneumonia, Still Birth of Twins - Twin to Twin Transfusion (1995), Chronic Fatigue Syndrome (1998 - 2003), Spinal Surgery with a double discectomy and laminectomy (2005), thyroid nodules and a goiter, Liver lesion and fatty liver, erosion of the oesophagus.
  - In the last 6 months have been diagnosed with a severe disc bulge/herniation C5/6, disc protrusions and disc degenerations.
  - In the last 3 months I have been diagnosed with Thoracic Outlet Syndrome and possible T4 Syndrome.

I have been working fulltime over the last 8.5 years and as of 1 April 2016, I have taken a redundancy from work, primarily as I cannot keep working at the job I do. I currently work in Digital Marketing with long hours and sitting at a computer all day, this is no longer sustainable and I am having to look at other career options. I had also attempted to study a Bachelor of Behavioural Psychology, however in 2012, illness forced me to indefinitely defer.

My life

Its very difficult to write my story, there are so many facets, so many details – the short version is, I'm adopted and have been very unwell for a very long time. I have now met my birth family who all seem to have varying degrees of normal illness but nothing like what I go through on a day-to-day basis – for which I am very grateful, I would not wish my health upon anyone.

I wrote the following on 31/01/13 and thought rather than me tell this all again, I would include below. Note: I will add in my updates since receiving treatment after.

I called this document "MY LONG BORING HISTORY" which to me it is, unfortunately however, it is a long boring history, of sickness and illness which I have lived and I hope one day I will get to survive. Please also let me add at this point, I truly am one of the lucky ones, and I count my blessings everyday, that I am active, mobile and can live my life and life a relatively full one, albeit a limited one at times.

Amanda Bramwell 31/1/13

I currently work full-time and study full-time and refuse to see myself as either an invalid or a victim. I am studying psychology in the hopes that I might be able to help those who suffer from chronic pain or illness as I know firsthand how debilitating it can be, not only physically but also emotionally. So I hope it is ok I have presented this message a little clinically.

I am not sure if you want or even need to know my long and boring history – but please find below

– maybe it will help??

I am 37 years old (now 40), with extensive history of illness, I'm going to "try" and give you the short version and I'm sure I will forget and leave out a ton of info (I tend to forget things.. it's what I do!)

Travel / Residential history:

- Lives in Adelaide, SA

- 1984 trip America (New York, New Orleans, Orlando, Hawaii) and parts of Europe for 3 months (age 8)

- Frequent travel to Mildura, Vic to see family - until age 13

- Some travel around Australia on holiday inc. Metro Brisbane, Gold Coast, Sydney and Melbourne

- Lived in Melbourne for one year 1998-1999

Current Diagnoses : Lyme Disease / HGE - Was given Clinical diagnoses of Bartonella and Babesia but Igenex IgG and IgA tests negative -previous exposure CMV/HHV-6/Epstein Barr/ C. Pneumonia

Brief (not) Patient history:

At various stages have suffered from a range of virus's / illnesses including recurrent chronic sinusitis, chronic bronchitis, pharyngitis etc etc..

Born 1975 - Adopted at age 2 weeks, no known genetic history - except mother suffered from *pre-natal lupus*.

Was diagnosed with hyper-hydrosis at the age of 1 month, my parents were told it was a very rare condition to have as a baby and I've been told that apparently perspiration used to "run like a tap" off both my hands and feet. I also had extreme nappy rash and was very sensitive to "everything" and was very bronchial.

As a child, I suffered frequent bouts of what are now called "stomach migraines", what was then called "growing pains" in the legs, frequent unexplained rashes, dermatitis on the eyelids, repeated bouts of chronic bronchitis and pharyngitis. I was also a bed-wetter until the age of 12 and was on medication which did little to help.

1989 – around age 14 - diagnosed asthma – I no longer have asthma unless I have a cold or bronchitis.

1990 – around age 16- Started menstruation, which was very debilitating and very painful. At the same time started developing headache migraines. Subsequently diagnosed by several neurologists as suffering "classic" migraines or genetic migraines. Have tried many preventative medications and migraine medications which have proven to be ineffectual or I have had adverse reactions.

1995 - Age 19 fell pregnant with twins. At 28 weeks lost both in a still-birth due to placental problems (twin to twin transfusion).

Also had enlarged kidneys during pregnancy.

At time of still-birth I was very sick a short time later (1 day later) and was diagnosed with pneumonia and suspected pulmonary embolism in leg which suspected went to lung. – I was on IV antibiotics for 2 weeks.

1998 – Rapid weight gain – no known reason – 30 kilos in 4 months. Was feeling fatigued all the time, was always "unwell", would suffer migraines that would last for a week at a time and have extreme generalised body pain with localised back and neck pain.

1999 – Injured at work – strained two tendons – 3 muscles and nerve in back/neck and left arm. At the time they could not find the cause of the injury however recognised that it occurred. I was told I have 30% loss of nerve reaction on left-hand side.

2001 – Diagnosed with Chronic Fatigue Syndrome - CT scan of brain finding arterial spasming.

Tumours discovered on thyroid, tumours then biopsied and found to be benign. No thyroid levels abnormal at time.

2005 – Diagnosed with L5/S1 disc bulge – had lumbar puncture/ Cortisone injection which made disc worse. Resulted in spinal surgery – Double Discectomy and Laminectomy. Neurosurgeon unable to explain why at age 30 I had such problems.

Since 2005 - I have been diagnosed with 3 more disc bulges and am currently in and out of a neck brace, on strong analgesics to manage pain and am due to see the neurosurgeon again after resent MRI result showing disc prolapse and slight impingement of spinal cord at C5/6.

- I have constant referred pain, numbness and tingling in the extremities including what I call a "hot tap" feeling, it's like someone is pouring warm water down the outside of my legs and most recently my arms outside and below the elbow. Half my 3rd, my 4th and 5th fingers are almost completely numb and I have little hot/cold sensitivity in my hands – however I have been told the discs that would cause that particular nerve reaction i.e. C8 down my arm is not affected in any way and my legs shouldn't still be getting nerve reactions like this after surgery in 2005.

Over the last month I have started to not be able to hide my tremors (especially my left arm) and have constant pins and needles and numbness in both hands. I have also had it pointed out to me (by my Lyme friend) that I have some facial paralysis on my right hand side – on the right side I have a lopsided smile, my face has dropped and my lazy eye is pronounced (when tired)

- I have an erosion of my oesophagus – GERD (no known cause) and various gastro problems, with lactose intolerance and gluten intolerance – I have had two endoscopies and colonoscopies – which have shown some nodules but apparently nothing too major or reasons for my pain/symptoms.

- I have been diagnosed with fatty liver disease and also a liver lesion – I have elevated liver enzymes. I have been told more times than I can count that I need to stop drinking and asked if I was a drug addict – and let me be very clear, I do not drink in excess or take drugs!

- I have recent elevated cholesterol – and have always watched what I eat being both lactose and gluten intolerant. I am currently overweight 90 – 95 kgs and cannot seem to shift it – no matter how hard I try. I was even going to the gym with a personal trainer 4 times per week, on diet shakes and would walk everywhere – the most I lost after 1.5 years was 10 kgs – then my lower back went bad again (dec 2010) and since the weight has come back on again.. even though I still calorie control etc etc etc..

- I have low blood pressure and have had this for many years – since at least 1995

- I have a multi-nodular thyroid and goitre with levels that are inconsistent. Mostly my TSH will either be in "normal" range or around 0.02 it tends to fluctuate. –I have seen 3 Endochronolisist's over the years who cannot explain any thyroid symptoms or test results. – Ive been tried on Thyroxine and felt AMAZING for all of two weeks then crashed badly and was taken off - I even had one Doctor put me on Metformin even though I had no Diabetes symptoms or related test results.

Dec 2011 - I suffered a painful injury by "just falling over" and badly damaged my ribs and costal cartilage. I also had fluid on my elbow from the fall – (I feel my body completely overreacted from the fall!!!) - one year later I still get spasms from the injury and still feel burning pain in my ribs (it's ridiculous).

Mid 2012 – experienced 3 months of feeling like I was on a boat in rough seas – really bad vertigo. Saw a Neurophysio who could not explain it – she said it might have been a vestibular issue but she was even more puzzled when it "just disappeared". .. lately I have noticed symptoms it may be returning.

Mid 2012 – saw an Ear Nose and Throat specialist for recurrent "chronic sinusitis" – she analysed a CT Scan from 2010 and said I didn't have any problems with my sinus – however I did have a bone spur and an "air pocket"? , deviated septum with narrow passages. She said my "sinus" issues could be down to maxio-facial pain but I would need to undergo septoplasty to fix the nasal spur.

Over the last few years, I have had multitudes of tests where I have been either in the upper limits or lower limits of normal – usually I am right on the line of being abnormal. Annoyingly, I also have tests that show abnormal but do not match up with other tests which should show the same thing and my tests make no sense to specialists.

For example, my last test of autoimmune antibodies showed I was 80 (right on the border of being abnormal).

Vision Problems - Additionally, I wear contact lenses, being long sighted and having worn glasses since the age of 6 - I remember at a very early age being given eye exercises to do to try and correct "lazy eyes". I have also had an astigmatism in both eyes – however, over the last year this seems to have corrected itself (the optometrist seems to think this could be because I now wear contacts). I am finding at the moment my eyesight is getting a lot worse and has very rapidly declined over the last two months, I now at times find myself wearing both contact lenses AND glasses as I just can't seem to focus. My eyesight has always changed every 6 months – but this is getting out of control!! I am wearing +4.5 contacts with +1.5 glasses over the top for computer work / reading.

General Everyday Stuff - I suffer from migraines, memory loss, fatigue, anxiety, random inflammation, excruciating and debilitating random pain , painful and heavy periods every 2 ½ weeks that last 10 days, allergies and psoriasis, sinus, brain fog and I just can't find words.. I stumble over them more often than not (my thesaurus is my best friend).

– This has also made me aware to tell you that every time I have ever had a migraine I have had some facial paralysis – usually on the right side – neurologists have been unable to explain this over the years and say its nothing to do with the migraine!!

I'm thinking as I have had a very busy life over the last few months, with uni exams, work end of year, buying and moving into a new house (December) and so much "stuff" going on, it has exacerbated whatever is going on with me.. my neuro symptoms have definitely got worse as has my pain level. I have never known a time I have not been in pain – but recently I am hitting new heights of tolerance.

Over the years, I have seen so many specialists who all disagree with different diagnosis and say "sorry I can't find anything too abnormal" and/or "well I guess some people are just unlucky".

Now I know it's Lyme and I just hope that I can be treated and have a good outcome. ☺

So that was my story at the end of January in 2013.

Since then, I started taking Doxycycline x 400 per day, as well as supplements, liver tone plus, magopti (magnesium compound), nutrition care gut relief (glutathione), Fortakehl and a probiotic intermittently.

I then went on to pulse Tinazadole – 2 weeks on/2 weeks off.

I implemented a strict regimen and worked very closely with a GP, Naturopath and a specialist in the US.

Fast forward to present 31/03/16

Happy to report that after 2 years of this treatment, not only did my liver levels return to normal levels, my lesions, shrunk, my erosion of the oesophagus healed and I have got much of my life back. I only ever get the rare migraine and the chronic fatigue / brain fog only returns when I'm over tired, stressed or overworked (something I am working on by leaving my fulltime job). I still have very painful menstruation – with no known cause and excruciating pain with my back, neck, legs and arms. I still see a physio once a week but am no longer in need of a "team" of doctors and am also no longer taking antibiotics. I still however take a lot of supplements to support my system in the hopes that I wont have another relapse.

My back/neck is steadily getting worse and I'm doing everything I can to stay off the "cutting table" by seeing a physio once a week and changing careers –at the moment have a vascular surgeon lined up and have seen recently an occupational therapist, a GP and a Breast Surgeon (due to thickened tissue and a mass which at this stage, may or may not be some form of something scary – yet to be determined).

I have to say, the worst past about this disease, is having to cover it up – I didn't even mention it to the Breast surgeon. I have been told due to my job that I was not to mention it – I worked at The University of Adelaide in the Faculty of Health Sciences, and was told by my boss "please don't mention Lyme Disease as not many believe in it". Not only was that awkward, it made things very difficult when I fell ill as I had little understanding.

I also lost my GP of 20 years to this illness. When my results came back I was told that she was no longer able to treat me. She said that there were no Australian Guidelines for her to follow and she was scared to work with any doctor who would tell her to prescribe medications because she "had a family to think about". That then led me to try doctor after expensive doctor and quite a bit of "quackery" along the way. That is until I fund a wonderful no-nonsense team who have helped me get to where I am today – still not 100% but I will take 70% any day over where I have been in the past!

As a final note, please listen to what patients are telling you, there is something out there that is really doing some serious damage, that with the right treatment and care can be helped.

If nothing else, think of the drain all of this is putting on the healthcare system, my case alone I know runs into the hundreds of thousands of dollars with surgery, hospitalisation, tests, specialists and who knows what else I will run into in the future!

Mildura – where it all may have begun?

I was in Mildura recently for my Aunties funeral and said to another auntie "how come all the mobility scooters in this town?" she replied with "Oh, the Lions clubs raise money for families as so many have MS". Here is probably where I mention that MS is commonly misdiagnosed instead of Lyme Disease. Incidentally one of my mum's childhood friends has MS and is extremely debilitated, his wife is his carer so neither are able to work – he is also from Mildura.

To my mind, Mildura is where I contracted my Lyme-like illness, and I would not be surprised with the amount of ticks in the Riverland. I spent much of my youth playing by the river and no one knew about ticks then, or even does now. It blows my mind that we have over 70 catalogued species of ticks in Australia – more than any other country, and yet we still like in the denial of even a "Lyme-like" illness, let alone the debilitating co-infections which we KNOW are here.

My Family

My (adopted) father has now been diagnosed with Progressive Supra Nuclear Palsy (PSP) which is commonly misdiagnosed as Parkinson's. Unrelatedly, my (adopted) mother's sister (my Auntie) was diagnosed with the same thing. They are not related by blood and this disease is apparently not inherited. However, PSP and Parkinson's, both known to be misdiagnosed instead of "Lyme Disease"

I would like to write a lot more about my family, but feel I cannot do so without their consent. I know however that from all sides of my family my illness has affected them and will continue to do so. I try and hide most of my pain and “just get on with it” but they know and I often get told they can “see it in my eyes”. Its not easy but I just keep on trying!

Thanks for reading and I really hope someone did! It means a lot to all of us that this enquiry is taking place and I really hope that we as patients can see some positive outcomes, treatment, appropriate testing and public awareness.

Many thanks,

Amanda Bramwell