

## SENATE ENQUIRY SUBMISSION

NAME: [REDACTED]  
AGE: [REDACTED]  
ADDRESS: [REDACTED]  
POSTAL ADDRESS: same  
CONTACT: [REDACTED]  
I WANT MY STORY TO BE: Public

## ABOUT MY JOURNEY

I ACQUIRED LYME-LIKE ILLNESS AT:

Either Ferntree Gully or Sassafra in Melbourne.

I had never left Australia until I got treatment in Hawaii October - December 2013

TYPE OF BITE: unknown

I WAS SICK FOR: 28 years and 5 months before I was diagnosed

I HAVE POSITIVE BLOOD TESTS FROM: Igenex

I TESTED POSITIVE FOR

Borellia Burgdoferi 31 IND, -39+, 41++, 58++

Human Granulocytic Anaplasmosis - A. phagocytophilum

I HAVE SEEN easily over 100 Doctors now in the 30 years I've been experiencing this:

- LDS Dr [REDACTED]
- General Practitioners 30+
- Specialized Naturopathic General Practitioners
- Naturopaths
- Neurologists x 5+
- Psychiatrists x 6 - Mental Health Case Manager
- Psychologists
- Social Workers
- Neuro Linguistic Programing
- Kinesiologists x2
- Reflexologist
- Psychic healers x 2
- Colon Surgeon/ Specialists x 2
- Rheumatoid Specialist
- Chiropractors x 4
- Chronic Fatigue Specialists x 2
- Physiotherapists
- Dietitians x 2
- NIS Osteopaths/ Cranial Osteopaths x 3
- Hypnotherapist
- Acupuncturists x 3
- Massage/Myo therapists x 5
- Reiki
- Iridologists
- Bowen Therapist
- many other I cannot recall

HOSPITAL ADMISSIONS: how do I start here, with 29 years of history and not having documented every incidence! Too many!

- \*age 13 [REDACTED]
- 27 \*MANY Emergency ward experiences
- \* The [REDACTED] lots
- \* [REDACTED] Hospital
- \* [REDACTED] Hospital Epilepsy Ward
- \* [REDACTED] -for borderline personality 8 months
  - Schitzo Effective Disorder
  - Multiple Personality Identity Disorder
  - Dissociative Identity
  - Bi- Polar
  - CONVERSION DISORDER!
- \* [REDACTED] Hospital Psych x 4 age 19/ 21/
- \* [REDACTED] Hospital
- \* [REDACTED] Hospital a few times
- \* [REDACTED] Psych ward
- \* [REDACTED] Hospital

I HAVE BEEN DIAGNOSED WITH:

- Chronic Fatigue
- Migraine
- Gut Permeability
  - Prolapsed and Lazy Bowel
- Systemic Candida
- Extreme Severe Irlen Syndrome
- MTHFR -C677 A1298C many other
- Fibromyalgia
- Cervicogenic Headache
- Mould
- EMF sensitivity
- Epstein Barr

PREVIOUS DIAGNOSIS:

- Temple Lobe Epilepsy
- Eating Disorders/ Bulimia after GI tract shunt down
- Depression
- Schitzo Effective Disorder
- Dissociative Disorder
- Post Traumatic Stress
- CONVERSION DISORDER!
- Food and Chemical sensitivities
- Light Sensitive Epilepsy
- Idiopathic Spinal Myoclonus
- Laxative dependence
- Hyperlipidemia
- Sciatica
- Fibromyalgia
- Subacute Thyroiditis / Thyrotoxicosis/ Hypothyroidism
- Hashimoto's
- Heavy Metal Toxicity
- Multiple Personality Identity Disorder
- Borderline Personality Disorder
- Bi- Polar
- Hypochriacism
- Pseudo Seizures
- Epileptic Myoclonus
- T2 brain hypersensitivities
- Asthma
- Blood deficiency
- Slipped Disks L3/4 L4/5 S1
- Subacute Thyroiditis/Thyrotox
- Graves

## THE TREATMENT:

\*Omizu Medical Sanctuary in Hawaii 3 months October to December 2013, doing the following treatment

- \* 21 days water fast 3 days fermented coconut water
- \* Intravenous Therapy
  - Hydrogen Peroxide -Vitamin C
  - Alpha Lipoic Acid -Magnesium
  - Glutathione Push -Nutrients
- \*Acupuncture
- \*Castor Oil Packs
- \*Colon Hydrotherapy
- \*Deep Tissue Massage/ Body Work
- \*Sauna and Guasha Skin Cleaning

## BASELINE HOME TREATMENT:

- \* Raw and vegan, any cooked foods affects pain levels and shuts digestion.
- \* Rebounder with Niacin Flush
- \* Sauna/ Bentonite clay/ Activated charcoal/ Shower with skin cleaning/  
Magnesium/ DMSO
- \* Baths- magnesium, bicarb, borax
- \* Diatomaceous Earth
- \* Oil pulling
- \* Fermented drinks
- \* Magnesium oil x 2 at least
- \* Cannabinoid tinctures
- \* Previously self administered Vitamin C IV and glutathione push, self
- \* Activated charcoal and Bentonite Clay
- \* Turmeric and Ginger
- \* Lemon and Cayenne
- \* Apple Cider Vinegar
- \* Kava
- \* Ferments- Kombucha, Keffir, Sauerkrate
- \* Heaps more thats interchangeable depending on situation
- \* Juices and fruit only feasts

Just began Dr Morse Herbs to restore bowels, digestion, adrenals, liver, kidneys, lymphatic drainage etc

## SYMPTOM PRESENTATION LIST

### AGE

- 9 back pain  
frequent night time bathroom trips 6 +  
clicking noise in ears when running or jumping, hurts and smells/ tastes  
winded  
elbows begin to lock up with no release. Eventually click (very painful)  
then release, goes numb and tingly afterwards  
skin becomes mottled in appearance for no apparent reason  
notice prominent nail ridges  
blocked fizzy ears  
constant snorting and coughing up of massive mucus chunks  
very sore neck and shoulders
- 12 Ground appears to dip and rise, I felt separated from my surroundings.  
This still happens now.  
Flourescent lights in primary school portable would suddenly stop my  
ability think coherently  
notice strange lump/growth/scab on head change sizes but not heal
- 13 Migraine                      headache                      confusion  
extreme light and noise sensitivity -causing nausea/ confusion/dizziness  
visual distortion      watery, wavy look.  
dark and wispy figures  
hands or shadows/creatures appearing out of nowhere  
pixelated look, blurry  
dipping and moving ground  
morphing features on scenery and people  
scenery moving like watery wavy effect (Predator look)  
halo effect on objects and schoolbooks  
sparkling white flashes  
vision disappears  
seeing double wispy etheric look  
poor depth perception, looks flat

Could see “ghostly looking figures walking through people, changing shapes of family faces. Familiar faces would look plastic.  
awake with night terrors and gasping for air.  
couldn't decipher the difference between real conversations and distorted weird morphed sounds of voices I couldn't see.  
emotion change to sad then angry, confused then collapse into seizure.  
seizures/ muscles convulsion light induced.  
memory problems - forget immediately after reading or learning.  
inability to find words related to conversations.  
altered slurred speech after seize.  
slight wheezing in lungs, asthma, huge barking cough.  
lips continually intensely dry/ sore and cracked with canker sores.  
face is always red as if I'm embarrassed.  
splotchy red skin rash everywhere in fluorescent lighting and before seizures.  
sclera of eye and eye rims go bright red in fluorescent lighting.  
light headed.  
brain fog.  
chemical sensitivity- migraine seizure reaction.  
inability to sweat.  
petrified of the dark as thats when I could see /hear and feel different presences simultaneously.  
suddenly very scared of heights (previously loved heights).  
very sensitive/painful shoulders and neck/ears.  
bone pain first only in hips, then all over body.  
chronic fatigue.

- 16 cholesterol high.  
flashy light patterns when eyes closed and wanting to sleep. closed eyes were brighter/lighter than open eyes in a dark room.  
uncontrollable and repeated hand movements occurred after seizures, visions and strange conversation with some type of identity, that I don't understand, were part of the post seizure mode.  
agoraphobia, panic attacks when world appeared (felt) to shake violently.
- 17 constipation, lost own ability to move bowels.  
pain in stomach region.  
hernia stomach.

loss of appetite/ felt toxic/ stop eating in attempt to clean out/ labeled  
anorexia.  
puffy face.  
extreme pain under RHS ribcage.  
night leg cramps for hours.  
severe fatigue.  
chilblains feet and fingers.  
white fingertips and toes -frozen.  
body temperature regulation broken, cooler than the ambient temperature.  
right hip pain- legs stop working, numb, spastic gate, RHS leg dragging,  
leg falls asleep, leg very heavy concreted weight feel, legs (at hip joints)  
comes out of joint with a loud clicking sound.  
sciatica.  
sudden body collapses, out of blue with an inability to communicate though  
still aware of people around me.  
night drenching sweats.  
no tolerance to spinning rides or swings, which were previously loved.  
notice bottom eye rim has raised broken blood vessels and bumps  
inside bottom eyelid.  
often go into trance like states and wake unaware of what I have been  
doing or how I got to places. Could recall a feeling of communication  
and being in presence of something, unsure of what! Woke smeared  
with blood.  
loss of appetite.

- 22 gums started bleeding and receding regardless of my standard of cleaning  
wake with loose teeth like I remember as child.  
extreme fatigue.  
excessive thirst 16 litres water a day.  
leaky gut.  
hair becomes very coarse/ wiry and curly.  
chronic fatigue.  
breathing spasms of throat (can get air in through nose yet throat is in  
spasm) similar to asthma.  
chilblains feet and hands in winter.  
chronic fatigue.  
loss of access to correct words, forgot people and names and any new info  
clammy hands.  
sudden intense shakes with dizziness.  
damp/ wet/ moldy areas (in houses) caused body extreme pain.

- 23 compacted colon continuos.  
thyroid hashimotos.  
leaky gut.  
magnesium Deficiency.  
candida.  
brain allergy.  
insulin dominance.
- 25 miscarriage etopic, sudden fallopian tube rupture, loose right tube, big blood loss severe pain, blood transfusion.  
apparent fallopian tubes damage, thought to be from bacterial infection.
- 26 infected ear drum bursts/ perforates.  
carpal tunnel.
- 27 geographic tongue.
- 28 smell and taste in brain before seizing.  
sudden feeling of gushing adrenal throughout body day or night.  
space out stare.  
pins and electric shock needles throughout body.  
body temperature regulation stuffed. Body temperature would soar from freezing to very hot within seconds especially after hot or cold drinks.  
cold and hot drenching sweats.  
notice blood flow pools in my lower legs/feet when standing still. Legs hurt and go numb.  
under skin I have a continual flicking twitching muscle sensation.  
very heightened sense of smell.  
very intense sense of hearing.  
head arms legs constantly jerking.

### 28-33 Hypoglycemia

- 30 skin face rash, watery and crusty blemishes, break, itch, red raw scabby.  
sudden collapse increased severe pain RHS under ribs, nausea queazy.  
bone pain like being sucked dry.  
increase swallow spasm /cramps.  
muscles begin to feel nauseous as if vomiting.  
massive change in intensity of agony pulling twisting weakness.  
rhythmic muscle contraction (great abdominal workout.. not!).  
burning acidic muscles like after a workout.  
have a deep heavy lead sensation.

feel squirming sensation like creatures, worms, spiders under skin.  
neck begins pulling back in seizures and cutting off airway.  
face dragging/ melting feel.  
agony in body with light touch.  
numb teeth and gum/ face.  
teeth clenching before seizes.  
muscle jerking and twitching continually.  
restless body sensation.  
feel very drained and shaky.  
face and eyelid color goes more yellow in tone.  
severe menstrual flooding.  
wind/ aircon/ all sudden temperature change reacts with seize and agony.  
cannot handle summer heat yet humidity is great.  
light touch / brushes against skin are agony and can restart a body seizing  
reaction.  
constant leg weakness, body overwhelms and collapses.  
wheelchair needs began.

31 Blood shows signs of continued problems with

-Neutropenia	-leucocytes
-platelets	-white cell
-thyroid	-lymphocyte reactive
-iron and ferritin	-leukopenia
-thrombocytopenia	

32 intense hair loss, hair becomes thin and frizzy.  
huge increase in noise reaction in jerking body.  
intensely forgetful of anything new.  
loose train of thought mid sentence.

33 slipped disk L3/4.  
intensified restless leg.  
severe high thyroid (3 months no more that 2 hours sleep)followed by  
low, Hashimotos. Thyroiditis.

34 food leaks/ (vomit) forced out when in body/ neck spasms cannot breathe.  
broken blood vessels over eye area and face after seize.  
feeling of slushy thick slow cold blood flow.  
very slow laboured movement. messages from brain to body not connecting.  
7kg sudden weight loss (after keppra and topamax)

environmental temperature changes (especially storms) create body seizures and intense pain.

wind causes body to freeze like a statue.

want to stretch continually to ease body pain, but with no relief.

begin walking on tops of feet.

no strength.

cold sweat perspiration has strange scent afterwards.

uneven ground or fast pace paralyzes legs.

ebstein barr anti bodies.

shingles right hip and abdomen.

constant numb/ tingling body, face, teeth.

35 enlarged lymph nodes.

38 live blood tests- fatty liver, no white blood cells, rouleaux, mycoplasma and other abnormalities.

39 endplate osteophytosis L3/4.

liver spots.

face rash constant has intensified.

feel of bones being sucked dry.

41 sudden brain shutdown presents like cerebral palsy.

suddenly loose power in entire body, powers up spasmodically then goes again.

vibration, sound, touch, startle shuts down nervous system causing inability to walk and talk.

severe sudden dizziness and intensified pain whooshing through body can cause me to pass out. Cant find any comfort whatsoever.

sudden eye pain.

body not bouncing back as in the past. body staying in high reactive pain.

thinning of eyebrows.

extreme sudden increase in receding gums and teeth are rotting quickly.

becoming more exhausted each day.

diagnosed with -Lyme and Anaplasma

-MTHFR C677T detected heterozygous

-MTHFR A1298C detected heterozygous

inability to detox effectively, body not responding to treatment and shuts down.

no idea where I am, in a limbo state.

bowels- diagnosis prolapse hemorrhoids mechanical problem.

brain continuously feels hot. A liquid burning sensation flows up my neck  
around right ear and across my forehead.  
unable to be hugged or touched without insane agony.

## LIFE PRIOR TO ILLNESS:

I was shy child, yet a complete adrenal junkie up until age 13 year old. Super excited about life and had an incredible massive passion to achieve becoming a super successful artist, the desire to play professional netball, gymnastics, loving life and all the awesome adventures of the outdoors. Running up and scaling trees and jumping from the top of trees onto a trampoline or shooting down a flying fox, motor bike riding, BMX jumping, underground cubbies, building tree houses, activities very much like how treetop adventure places are run, but without the safety equipment! Loved wizzy dizzies and anything that would induce that kind of woozy sensation! I loved socializing and joking around with my best friends, always attempting to make them laugh.

## THE EXPERIENCE:

Mum and I were driving home, suddenly it was as if I morphed out of reality. I lost perception, visually warping into the flashing distortions of the sunlight through the gumtrees.

Complete pounding confusion flooded throughout my being. It sounded as if I was breathing underwater, ambient sounds were unrecognizable, morphing into a very scary chaotic blur. With weird sensations of pressure in my head and ears my legs then collapsed upon my attempt to get out of the car. The usual soothing sound of mums voice was strangely terrifying. Fear engulfed me as I lost complete control of every part of me. What was going on, how did this happen, why was I suddenly so incompetent at controlling my body?

What was creating such violent body spasms, when I was seemingly fine just beforehand. Wasn't I?

About 4 hours later it stopped, beyond the explanation of exhausted, when I attempted to communicate my voice was totally deformed. The pain in my head was indescribable. My family members looked plastic and unreal. I could not recognize my mother, she looked like a swamp monster and I wanted a knife to protect myself from "it".

I thought this was just some kind of freak occurrence and that would be it.. But life devastatingly changed that day forever.

Looking back it possibly was building years before when I stopped gymnastics due to severe muscle pain and I had the beginning of strange fizzy pain behind my ears and weird sensations in my ears for years. I was also a very mucus/nasal problematic, food and chemical reactive child.

At this initial time, I was labelled with temple lobe epilepsy. However the medications didn't work and I still continually suddenly dropped, no matter how I mentally attempted to have body control, it was fruitless and seemingly had an agenda of it's own.

School became hell. I was collapsing a few times a week through any kind of florescent light and flashing sunlight. My ability to communicate with my peers was non existent, my brain was blanking out from transmission continuously. This led to torment by my peers who teased me constantly.

Continual migraine, headache, extreme light, florescent lights, EMF sensitivities totally changed my world. I was drenched in agony. The next year came incredible hip agony, that I now know to be bone pain. It shut me down continuously, as my hips always gave out and the pain and sciatica stopped me immediately. The agony continually intensified and built in ever more strange ways over the years.

Heartbroken in many ways. My Dad soon became tired of the same old seizures and lost belief in my sanity. I saw his disgust and resentment when he looked at me, it was devastating.

He requested I be put in a Psych home so the family could get on with their life. Dad felt left out as Mum spent so much of her time seeing to my health. Years were spent with my Mum comforting me to sleep, and rushing in with my continuous night terrors.

I was beyond terrified. I felt I was loosing my mind in the whirlwind of agony mixed with continual terrifying auditory and visual distortions. Faces looked as if they were melting, like my world was visual dyslexia, nothing visually stayed still. Watery waves, dipping ground, visual whiteouts, strange sparkles, no depth perception. I was continually dizzy and almost passed out each time I stood up.

Attempting to sleep was harder than my previous childhood insomnia. Closing my eyes was like a light show of fireworks, a weird fractured kaleidoscope of flashes, lighter than when my eyes were open. People looked fragmented and that mixed with the distorted hearing, was like living my own continual horror movie. My world crumbled severely .

To see the pain of helplessness in Mums being was horrible. But she helped me more than she possibly understands throughout the years. Guilt was overwhelming as I felt I was tearing my family apart, all because of some stupid inability to control my mind and body.

The continuous teasing traumatized me deeply, I didn't understand how I was suddenly so unlovable. I had 2 best friends at the time this began, one friendship disintegrated not long after the seizures began. The other moved away. This on its own was shattering.

My personality changed considerably, as pain shut my usual fully adrenalized adventurous self down to a soft glow.

Being a 13 year old is hard enough without the added peer group pressure. Although I can now appreciate why the torment and continual teasing occurred throughout my school life, I am still breaking free of the trauma to my psyche and the ability to fully expressing myself without fear of rejection..

Mum and I have been on a constant mission since to discover the truth in what was happening to me. So many more Doctors than I can recall, we went mainstream with no answers and alternate healers of many teachings. With pretty much every test under the sun. The disgusting treatment had me give up on Doctors.

I've continually lost friends throughout my life due to how all encompassing the effect this has on my ability to socialize and how challenging it is for others to understand the enormity of it all.

People gave up and stopped believing it was real, as it was such a long undiagnosed sickness the assumption was that it was psychological. It completely dulled my personality. I wasn't energetic enough, was physically unreliable and didn't fit into their perception of fun, with the get drunk and party hard scenario. Now being a non drinker it's about people actually asking me out, knowing it could end up as a carer role isn't very enticing for them and some don't know how to deal with the intensity.

The misconception of why I had to live such a clean lifestyle also came under severe scrutiny, I was continually confronted and regarded as mentally unstable. Questioning how could I be so sick with such a pristine lifestyle?

The saddest thing is that this disease is more than just the crushing breakdown of body, emotion, confidence, esteem, lifestyle, perceptions of success etc of the person experiencing it. Everyone is affected. It's an emotional tsunami of horrific effects in every aspect of that persons life: their immediate family, children,

friends, relatives, the society of judgements and the totally disgusting treatment from the medical system.

Such an impact on my nervous system had me not being able to stand up for myself in so many social circumstances.. Any sudden startle, shocked my nervous system into malfunction, then suddenly took my my entire system down. Resulting in loosing my ability to talk, walk, run and say no to sexual advances. A perfect ground for the many horrific sexual assault experiences. Complete communication capacity was gone, lost to the onslaught of intensified pain and complete shutdown that became seizures.

I couldn't deal with the anguish of my Dad not believing in my rapes and other continuous sexual assaults that happened while at Uni and socializing etc, because of my body suddenly seizing. I had total disgust of myself for being such a failure. Why could I not stand up for myself, where did the sound of my screams of help disappear. I didn't understand why the intense passion and dreams of success I had were continuously psychically shut down. I had had enough. No one wanted to hear my truth. I had become an apparent joke, a hypochondriac.

I didn't know any emotional skills to relieve my agony at first. So I started with befriending alcohol, smoking, cutting, and now the friendship where bulimia and anorexia became intentional; (at first it was to stop the agony in my shut down Digestive System). Along with my mammoth pain relief use from the years of being prescribed opiates for intense migraine; these in the end only solidified and intensified my body pain, so I weaned myself off them and went drug free. I had many people take me into emergency, only to hear the nurses state that I "am a useless drug addict, look at her dilated eyes, she's of her head, she's a waste of our time," (as they pushed there thumbs deeply into my eye sockets and finger nails into my earlobes into attempt to wake me out of faking it) "There's nothing wrong with her other than her want for attention. And why are you here if you don't want pharmaceutical pain relief?" Mmm, lets see, maybe a real answer would be amazing!

Many Neurologists laughed at me when there was an extreme change in my body state from reactive to more calm through the switching on and off of the florescent lights. Dr ██████████ purposely set up scenarios to test my "hypochondria" and smirked and sniggered with amusement.

I was accused of taking thyroxine to induce an extreme hyperactive thyroid. The Doctor stating "you have previous mental health issues, stop doing this for attention".

This depreciation in believing in me, and the very abusive nature of my ex husband, finally led me to attempt suicide. I tried a few times.

This I did in an attempt to gain relief from the agony. I was trying my best. I didn't want to die, I wanted the abuse of my ex and the body pain to stop. Suicide was the only way I could see as a way of escape from both the abuse and pain. I wasn't purposely intending to harm myself. It became an emotional coping mechanism, as no one believed anything I said.

I desperately wanted to live a normal life where people believed in me and with no agony. I wanted the true loving essence of my being to be known. I felt and loved with a passion. But I had also learnt a betrayal of the belief in who I was, through the various gut wrenching experiences I had.

HORRIFIC, when I was asking for help from abuse, it was put down to me just wanting attention.

Mental Health labels further increased social isolation and stopped any doctor taking my health issues seriously. This further compounded my own betrayal of believing in myself. Therefore I decided I must be worthless and unlovable. Especially as my Dad was disgusted in his perception of me, of how he thought I lied about sexual assaults and the family violence towards me by my ex husband, as though all I wanted to get his attention. No one was listening, it all just came down to mental health problems. I welcomed that label with excitement, thinking that the system may actually offer some help to resolve my pain, wherever it was came from.

The flawed Psychiatric System only forced me onto medication each time I was admitted, which only created more toxicity and agony. They really couldn't care to offer solutions, other than that of shutting me down through medication and telling me I would always be tainted. Age 33, I was told "if I refused medication, that I'd be committed and never able to be a hands on mother to my son again."

I began learning more about lifestyle and food choices and have continued to learn even deeper understandings of living a super healthy lifestyle since age 22. I really credit the knowledge of this lifestyle to keeping me alive, and keeping a hold on my frail health that I have. If I eat any tarnished food I'm instantly in the deepest agony, vomiting and have seizures.

The agony and toxicity continually built up in my body. I wanted to work and attempted various jobs. But I couldn't continue as my body keeps shutting down, this is caused by exhaustion and through florescent lights. I tried working outside in vineyards and fruit picking and only ended up in seizures. Its haunting, knowing I wanted more than I was physically capable of. I strived so damned hard and no one could hear my cries.

I hate being dependent upon the government or on anyone else for support. But due to the nature of this Lyme-like disease and the lack of acknowledgement from the government I have no option.

After 2 miscarriages and an etopic miscarriage over 5 years, I eventually had my gorgeous son, followed soon by a horrific marriage breakdown. That entire relationship breakup was construed to me being irrational, due to seizures and all my apparent labels. My exhusband moved to Queensland. I began having intense seizures again, and my young boy became like a carer at age 3, making safe and ringing Grandma when needed and still does to this day. I ended up in a wheelchair many times, starting 13 years ago.

My family didn't believe in me as my ex so effectively used my health situation to undermine my emotional integrity, which then flatlined my entire friendship network a few times, except for one friend .

I was put on epilim for light sensitive seizures and seroquel from the mental health department for psychosis (and copious other forced medications). Many tests were inconclusive other than the constant years of low white blood count, neutrophils, platelets, thymbocytes in my blood. That was dismissed by a blood specialist as being "my normal".

While in one of the many hospitals stays for intense agony it was found that I had extreme neutropenia through the epilim and was immediately taken off my high dose overnight. The Doctor also stated that I have a mental health history and was creating my symptoms for attention and that my inability to walk was mental.

Seizures then intensified to everyday due to the sudden withdrawal and I was placed into a week stay at the [REDACTED] Epilepsy ward. 7 days of no sleep later, it was decided that it was all pseudo seizures and that because I had expressed I was concerned my seizures would put my son at risk I lost the rights to looking after him. The Department of Human Services came in and very bluntly told me I was too mentally unstable to be a good mum.

Devastated, I still thanked them for thinking they were doing the right thing, but they were however mistaken.. 2 weeks later they allowed me to see my beautiful son and changed their minds saying I was a fantastic mother and was able to look

after him full time again. However my son's Dad had got in on the act and stated I'd never see my son again. This is also when when Mental Health became fully involved, stating I couldn't look after my son with all the mental health conditions and my apparent psychosis, unless I did a 7 month stay which ended being 8 months in [REDACTED] (a Borderline Personality Psych Ward). I told them I felt the apparent psychosis was just normal human emotional reaction to deep trauma due to severe unacknowledged abuse. I agreed to the stay eventually, because they said if I didn't I'd be committed anyway. I had now become conditioned to believe that maybe I was schizophrenic and totally delusional and desperately wanted to find the solution.

My ex was intensely abusive at this time, he moved back to Victoria from Queensland to look after our son. He illegally went to my Case Manager many times to illegally gain information from her about what was happening to me. He used this information to stop support from my family and social support networks. The Case Manager illegally gave out my private information to him.

He told the Case Manager that he loved me and was actually supporting me. In fact he only wanted total control of me. He did not tell her that he broke into my home and sexually violated me numerous times. He told her that any claim I made against him was just my psychotic mind distorting the situation. I fell pregnant through his abuse and needed an abortion..

Mum found out my reality after my 3rd suicide attempt and we began to heal our relationship. Which was just the desperate safety net I needed to remain buoyant in my turbulence of physical and emotional exasperation.

My Case Manager didn't believe me either, until the day of my restraining order. Then she couldn't stop apologizing and quit mental health job soon after.

My Case Manager then supported me, she stopped me from being fully committed to the institution because I had taken myself of the seroquel. I took myself off seroquel as it actually exasperated the severe body spasms I had and it intensified my inability to swallow and breath.

My Doctor laughed at me saying I'd be committed in 2 weeks and that I was on a high. The nurses totally denied that I had a medication reaction to seroquel. I totally disagree with the way this system is taught, in that I would always be in an emotional deficit and need to rely on medication and trust on an outside opinion over my own instincts and ability to heal. I do, however, credit it to beginning to wake me up from the stupor I had about my own worth. Hearing the devastating stories of others who punished themselves because of the insidious trauma inflicted upon them (many with lyme like presentations), had me realize that they

were just a reflection of the abuse I was inflicting upon myself. I decided to stop burning, cutting, bulimia, smoking and drinking (reintroduced from sheer mother agony of losing my child) overnight. I felt the agony instead of fearfully denying it. It was a super emotional exorcism! But I mostly loved myself throughout that poisonous feeling.

Time has proved both the doctor and nurses were wrong. I am now totally free from all medication, psych and other, and although I am still in pain, my body is functioning better without the toxic medication.

When I finally got out of that institution, the promise of me having access to my son was completely denied. My Lawyer said I wouldn't get him back for at least 7 years until he could decide for himself, as I had Mental Health labels.

Regardless of if they were relevant or not. I felt totally lied to and betrayed yet again.

I sacked this lawyer, learnt some NLP and got another Lawyer. At the mediation session, attended by both my ex and myself with our lawyers, I managed to get access to my son. This was all due to my own input as my ex had given strict instructions to his lawyer that I was not to get any access at all to our son. This was just another attempt by my ex to get total control of me. It took another year to get the full share care time, but my heart felt the deepest of peace imaginable.

After this I continued having ever more persistent violent seizures and looking for answers. I asked to be checked for fibromyalgia, but that Dr stated I'm too happy to be in that much pain.

Little did he appreciate the sheer exhilaration I gained by being able to see my son again, without a nominated amount of time and someone watching my every move.

My last admission to ██████████ Hospital emergency was in July 2014, (always against my wishes as I really don't want to hear their inadequacy), resulted in The Infectious Diseases Doctor stating to my mother, whilst shaking his finger in her face, that "This is a government run hospital, the government pays all our bills, the government says there is no Lyme in Australia, therefore there is no Lyme in Australia". Then he turned to me and said to me (whilst I was having a seizure - during my seizures I am conscious and am able to know what is happening around me, although I cannot contribute anything). He said " If you have had Lyme for 28 years you're stuffed so what are you here for anyway?". Then he told us that as I could not take any toxic pain relief medicine the hospital could not help me and I must leave immediately. Then the Emergency head Doctor stating that it was definitely under the banner of a hypochondriac, whilst giving me a referral to a psychiatrist. He also attempted to straighten me out my completely rigid body in

the midst of a full blown seizure, agony! My screams were heard in the waiting room by my girlfriend who had come to the hospital as a support for me.

Days later it was confirmed through Igenex I tested positive to Lyme Like Disease and Anaplasmosis.

Im now nearing 30 years since my first seizure and was only diagnosed 29th July 2014.

### THE IMPACT:

I feel like I've lived a lie, caged away in the shadows of my true potential. Corroding and morphing in a deep hollow abyss of agonies. Deeply ashamed by my own lack of ability to achieve all my desires. The lack of belief in myself, continually compounded through the disbelief by the medical system and the constant social ridicule, which had me believing I was making it all up. At times so riddled by the disgust of myself so much that I wouldn't ask for assistance when needed. A few times resulting in seizures, being stuck in the same position for the complete day, unable to move, speak, go to toilet, phone for help with vomit filling and burning my seized open eyes and struggling to breath.

The trauma of this condition is horrific, yet the disbelief in my person and betrayal from family members is what has been the most traumatic.

There is so so much to write, I've left out so much abuse from the system and other experiences, however the general imprint of my experience is stated. I'm so so thankful I made it through the immediate danger and strive with all my depleted strength to resolve this health state to show my son just how amazing a life we can create.

Somedays I'm completely stopped in my tracks, energetically flatlined, with the surging agony that overwhelms and imprisons all capacity to move, think, communicate, eat, struggling to breath, my digestion, absorption and elimination function stops continuously, I need to be carried, assisted and looked after. I'm not as bad as I was before treatment, however I am continually living in deep pain and have the occasional sudden no warning seizure.

Most days I cannot think straight and any attempt to do mental activities is very depleting and totally wipes me out.

I push 100% energy just to attempt a normal appearance, then magic some more energy in the attempt to achieve anything. Then it's totally downgraded by those who say, "When are you going to do and achieve something with your life?" Especially when they only see you when you are having a semi ok day, never the after affect of being social, or when you look like death. Being alive is a success.

As if not realizing my dreams doesn't frustrate **me** more than any onlooker! I've never got to realize my full potential. Never got to show what I'm fully capable of. I have an incredible wealth of knowledge and intelligence in tiny snippets of clarity that is then shutdown in the deepest volt of burning pain in my brain. I only gets quick snippets of clarity before its gone. My passion to succeed is abundant, yet lies dormant in me. I've really not known who I am without this.

I feel as if I was 13 then woke up almost 43, to an aged and decrepit state! Where is that missing time, other than marinated in an ocean of the deepest anguish of despair, agony and betrayal.

This wounding floods everything, just as deeply and indescribably as the agony. A family, friends, medical system and social outcast. The sheer cruelty of immediate family members attitude and denial of my moral and integrity. The only medical area that welcomes, is the Psych system stating I'm mentally unstable. This does not relate to my state of being so I don't welcome it. It only pushes unwanted medication on me and they still too constantly laugh in my face because they've decided it's hypochondria after seeing the Mental Health history and they immediately switch off. If I had listened to the Psych system would not be alive today.

Before diagnosis, being told that you come under the banner of hypochondria in ██████████ Hospital, only to find out 10 days later it's actually a tick pathogenic bacterial infection undermining your every part and your rapidly depreciating and near loosing the battle of life.

The interpersonal sadness as I've treated myself so cruelly believing those opinions. My bodies broken ability verses my intense passion to succeed and achieve all my dreams and aspirations, constantly shut down physically and mentally.

Experiencing life on the tentative edge, never knowing if my body is going to suddenly shut down. Having this lack of medical systems care land me into a wheelchair with full time carers throughout my life and the near loss of my life. The dreams I had of showing my son the world and being a brilliant active adventurous mother, rather than he caring for me. This is the highest feel of devastation and guilt. The frustration I constantly feel through letting my son down with our planned activities, time and time again.

## FAMILY

My son is an angel. He has incredible understanding and patience that melts my heart. He continuously misses out on experiences more concerned about my staying safe and making sure I'll function somewhat the next day, rather than risking situations that he feels may be too much for where my energy levels are. He is deeply traumatized each time he sees the sudden shutdown and is hyper vigilant in how he susses each moment.

This chocks me up incredibly, seeing the deep wounds of concern in his eyes and knowing how heavily this weighs on his heart. Missing out on the wonderful experiences we dream of achieving due to the financial restrictions.

My mum is a superhero. Working two jobs to make sure I can have the much needed medical care to heal this. Without her I wouldn't have survived this long and my son would be without a mum. She's always continuously filling in my bodies short falls, running around after my needs, cooking cleaning and not long ago being my live in carer, assisting with showers and dressing, feeding and taking me to appointments etc. On top of all this, she has responsibilities to see to in her own life. She is an incredibly strong person. All with the adversity of hearing her siblings telling her I am using her, making it up, a drug addict and that she only supporting my lack of mental health.

I have gained back my relationship with my older brother, however I'm not welcome by his wife.

My father says I'm apparently estranged, he wants nothing to do with me.

My younger brother has no concept of wanting to know about this situation and no desire to have a relationship.

Aunties and Uncles smirk at me a if I'm insane. Have stated it's "because I was on drugs", I was never on illegal drugs . When told I was dying, one Auntie told me "Everyone has their use by date" in disbelief of my condition and they feel I am mentally unsound.

## CAREER

Non existent at moment. It's exciting when I can unite my brain and bodies abilities to be able to paint!

Feels like a failure and it has been embarrassing for years not knowing what to say when people ask what I do for a living! This life is a fake compared to what I am passionate about achieving.

## ACTION I'D LIKE TO SEE HAPPEN:

STOP wasting time arguing over the bacterial name

START recognizing and treating. Acknowledge this is a very devastating reality and no one is immune.

TREAT people humanly and respectfully, regardless of whether doctors understand why patients are in agony if tests come back inconclusive.

TEST people as a general routine after a bite or when such an expression of long term agony is experienced. We cannot all be crazy and imagining the same symptoms. General checks in Mental Health Care system as many there present with Lyme-like symptoms and therefore should be tested and treated appropriately.

ALLOW Doctors who really care for Lyme-like patients, to treat them in Australia, without the fear of retribution because they choose to honor their oath in doing no harm.