25th January 2015

Committee Secretary
Senate Community Affairs reference Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Re: Senate Inquiry – Growing evidence of an emerging tick-borne illness that causes a Lyme-like illness for many Australian patients

Dear Senators,

Thank you for the opportunity to make a submission to the Inquiry. I request that my name be withheld from this document, and that Attachment 1 and Attachment 2 be completely withheld. My submission is outlined within the following pages:

1. Overview

- It is time to stop debating whether Australian ticks have bacteria that are making Australians sick, and focus on treating sick Australians!
- This submission has taken me in excess of 25 sessions/40 hours to write
- I am living proof that Lyme-like illness DOES exist in Australia
- Images of me before my illness and during my illness are provided (refer attachment 1)
- I have been published in a number of recent media pieces (refer attachment 2)
- I am currently 34 years old and live in [redacted] NSW
- It took approximately 2 years to diagnose Lyme-like illness. During this time I attended 178 appointments, approximately 88 of which were doctor appointments. This equates to about 1 appointment every 4 days for 2 years. I saw approximately 13 doctors and 7 allied health practitioners
- In total I have seen over 25 medical and allied health professionals throughout my journey
- My Lyme-like illness was finally diagnosed by an American-based Medical Doctor
- I do not recall a tick bite or ever seeing a tick and have never had a ‘typical EM bullseye’ rash
- Place of acquisition of disease is known, although I do recall a bee sting on the ANZAC Bridge, Sydney, where I developed a rash followed by cold/flu like symptoms and a cough that I have never recovered from. My health declined from this point. I have travelled within Australia and also internationally and have been bitten by a number of insects including mosquitoes, flies, ants, mites and fleas
- I have a positive Western Blot and Babesia Mictori test results via igenex USA
- I have positive diagnoses for Mycoplasma Phenomena, recurring Epstein-Barr Virus (EBV) and Sjogren’s Syndrome (Autoimmune disease) via Australian laboratories
- I have been admitted to hospital once for a potential reaction to a chelating medication
- I have been denied Lyme-like illness testing by one Australian Integrative Medical Doctor/ General Practitioner (GP)
- I have been denied Lyme disease/coinfection medications by 2 Australian General Practitioners (GPs)
- I have been denied further medical testing by two Australian specialists (Gastroenterologist and Immunologist)
- I have been denied an appointment by 1 Australian Infectious Disease Specialist (didn’t return phone calls or email requesting appointment)
- I loved life before I became ill and I am doing everything in my **control** to regain my health, wellness and life back
- I have an enormous respect for ALL current Australian Doctors and practitioners who treat Lyme/Lyme-like disease in Australia. Without their support, guidance, medical advice and onsite treatments, I truly believe my health would have deteriorated to a point where I would no longer be able to walk, talk or feed myself
- The cost of my treatments is hundreds to thousands of dollar per week and I am unsure how long I will be able to afford this treatment – which is keeping me alive
- An Australian GP told me that Australians with Lyme-like disease are by far the sickest in the world
- I need you, my Governments’ support and so do so many other innocent and suffering Australians

2. Journey

Since falling ill in 2013, I have been living a nightmare. A nightmare that is more painful, horrendous, heartbreaking and challenging than anyone can imagine or describe. Despite this, I will do my best to describe some of it to you.

I feel that my journey is not any more special than other Lyme-like illness suffers'. Sadly, as I have engaged with Lyme-like illness suffers over the past 6 months, it became very clear to me very early on, that my story IS all too common.

My journey has been time consuming, delayed, filled with misinformation and costly beyond what you could imagine.

It all began in 2013 - an amazing year for me. Whilst it started as the best, it became the start of the worst. I was on top of the world in my personal life, career and health and nothing could stop me… or so I thought!

Apart from two seemingly insignificant events (possibly unrelated to my illness) including a bee sting on the Anzac Bridge in approx. Feb of 2013 and a cold in May 2013 lasting only a week, a small cough began and lingered for months. This didn't stop me enjoying great physique and fitness with almost daily boot camp sessions and 40KM cycles across the Harbour Bridge every Saturday morning. I married my partner of 8 years in Port Douglas Queensland, had a load of vaccinations for my honeymoon in Africa, and reached the top of my corporate career with 2 of 4 individual awards for the company I was working - Employee of the Year (voted by all staff) and Outstanding Achievement (voted by management). I enjoyed wining and dining a few nights a week and was so motivated and driven in everything that I did and always had a smile on my face. My thirst for life was abounding with energy and positivity.

Upon returning from my African honeymoon in August 2013, fatigue very slowly creeped in over a few months and by November I started to have cognitive decline with a clear MRI scan but positive bloods for Glandular Fever. As per my GP's feedback I 'took it easy' and improved my diet over a few months.

In January 2014, after three months of no relief from the fatigue and cognitive decline of Glandular Fever, I sort out additional practitioners and tests. I was then diagnosed with Sjogrens Syndrome an Autoimmune disease and was told by various GPs and specialists this was the cause of my symptoms.

My symptoms progressively go worse and I continued to seek further medical advice and tests. I had a 'gut feeling' that there was something underlying and causing all of my illnesses and symptoms.

2.1 Appointments

I had approximately 178 appointments, including blood tests, GP, specialist appointments and additional allied therapy visits **up to the point to diagnosis** – all within Australia. That equates to approximately 1 appointment every 4 days over my nearly 2 year journey for a correct diagnosis! This included me enduring:

- Approximately 88 GP & specialist appointments before a correct diagnosis, including seeing 12 General Practitioners, 1 Immunologist, 1 Rheumatologist, 1 Gastroenterologist and 1 GP/Integrative Medical Doctor
- The governmental expense up to the point of diagnoses is HUGE - had the publicly funded specialists, testings and General Practitioners I attended, looked for Lyme, this could have **saved the government** thousands and thousands of dollars and wasted time
- Allied therapists included 3 naturopaths, 2 Traditional Chinese Medicine & Acupuncturists and an Esoteric Healer for emotional support totalling approximately 40 appointments
- Approximately 50 tests including blood, urine, stool, colonoscopy, endoscopy, MRI scan and several x-rays

- Contacting an American Doctor who recommended a number of American blood and stool tests which I completed, totalling approx. $1000AUD plus the Igenex Laboratory Australian Panel 3 Lyme test which was at a cost of $2000AUD
- Diagnosis of Lyme-like illness from my American Medical Doctor
- Various time delays between each practitioner including up to a 5 month wait for a GP treating Lyme disease, and another GP treating Lyme disease being inaccessible
- Thousands and thousands and thousands of dollars worth of out of pocket medications, treatments, tests, supplements etc

By March 2015, I was no longer able to work (and have not been able to work since). Two months later, after over 18 months of experiencing horrendous symptoms, as outline on page 9-10 and the ongoing doctor appointments and tests, I was desperately seeking another practitioner. I knew that something was still 'not right' and something was 'seriously wrong'. I attended a forum/conference on gut health called the MINDD Forum, where I meet both an Australian and American doctor. I booked both practitioners first thing Monday morning for their earliest appointments; the GP/Australian Integrative Medical Doctor treating Lyme disease was a 5 month wait to see and the American Medical Doctor was only 2 weeks.

Following sending all my records and a Skype consult, the American doctor requested I have a host of tests, one of which was a Lyme test. I questioned this as I have never knowingly been bitten by a tick – in hindsight I had classic Lyme-like illness symptoms which any GP treating Lyme disease would be able to correlate to Lyme-like illness.

Once diagnosed I felt I had no choice but to seek treatment with my doctor in America for one week, in which I travelled to California on my own at a huge financial and physical cost.

Since returning from America, I continue to work with my Medical Doctor in America and I am also very fortunate to work with 3 GPs treating Lyme disease within Australia, with whom I see weekly. I also have three sympathetic General Practitioners whom I see for various follow up blood tests, but whom do not know about how to treat Lyme-like illness.

Sadly, since falling ill, I have been denied care by a number of times by Australian practitioners.

2.2 Denied Medical Care

Details of how I was **denied medical care** over the two years **<u>prior to Lyme-like Illness and Coinfection Diagnosis</u> (prior to July 2015):**

- December 2014, when I consulted my first GP/Integrative Medical Doctor about Lyme Disease and whether I should be tested, my practitioner replied 'you haven't been bitten by a tick so you don't need to be tested' and secondly, 'I'm not going there as the government does not believe in it and this could affect my practicing, let's move on'. Had the GP been educated and supported by the Government at the time, I could have saved me and the Australian Government thousands of dollars, extra doctor visits and further disease progression with accurate testing.

- Early 2015, I was experiencing various gastrointestinal symptoms and requested various blood and stool tests from a local GP based on these symptoms. The GP refused to approve the testing and referred me to a second Immunologist, so as to 'move' me out of the practice. I was requesting these tests, so I could take them to a specialist who could interpret them, as opposed to waiting months to see the specialist, whom would then request the tests, hence delaying the process. I did not visit this practitioner again, as I felt they were not going to support me.

- May 2014, a leading Immunologist diagnosed me with an autoimmune disease. When questioned about the underlying cause and sudden onset of this disease, no explanation was given and a request for further testing was denied.

- April 215, a leading Professor of Gastroenterology reviewed my prior tests and conducted an endoscopy and colonoscopy. He didn't find anything untoward and advised there was 'obviously something wrong with my gut flora'. Refusing to do any further testing he provided me with a load of medication to continue to 'kill' my entire gut flora – in the hope I would get better or proceed to a faecal transplant, again 'in the hope' that this might improve symptoms.

- Various GPs have approved me to have TSH testing, although because this test is often 'within range', T3 and T4 testing has not been enabled. Although upon request and often expense to myself, my T3 has actually been outside of range!

Details of how I have been **denied medical care** **since my Lyme-like and Coinfection Diagnosis** (from July 2015):

- August 2015, 2 General Practitioners refused to prescribe a 21 day course of Wellvone (Atovoquone) and Oral Azithromycin, as they were not familiar with the medication or Lyme Disease and the Babesia Coinfection, even after I advised them this medication was standard practice in America and internationally
- 3 General Practitioners (including the two mentioned above) have all indicated they do not know about Lyme-like illness and coinfections and I should seek advice from a 'Lyme Specialist', although they are unable to provide me with appropriate 'Specialists'
- Approx October 2015 - One of the above General Practitioners provided me with a referral to an Infectious Diseases Specialist. I have emailed him several times, called (phone rings out) and had another GP leave a message on his personal mobile to contact me regarding an appointment, to which I have not had a reply
- Once diagnosed, I have contacted two of my previous and long-standing Alternative Therapy Practitioners (Traditional Chinese Medicine /Acupuncturist and Naturopath) and advised them of my Lyme-like illness diagnosis, to which they both replied with statement simular too, 'I haven't worked with any clients with Lyme Disease and I don't know how to treat it'
- Due to ongoing Intravenous Nutrient sessions (1 to 2 per week), my vein health has been deteriorating. A possible solution for this is to get a 'PICC line'. I have been told that I am not allowed to get one for the sole purpose of IV nutrients, and that I need to be on antibiotics before I am entitled to get a PICC line.

2.3 Currently

- I am unable to work, and am full time carer for myself
- My days are spent resting, doing various treatments (such as daily enemas, meditation, saunas, afternoon naps), taking my medications (at over 12 different intervals throughout the day), hydrating myself, cooking and preparing all my own organic food from scratch, researching treatment options to implement and further discuss with my GPs, purchasing food and purchasing my medications/supplements from over 20 different suppliers, writing notes on my progress for my GPs, booking appointments, having medical tests, communicating to other Lyme patients about treatments that work for them, including exercise/movement in my day
- All of the above is very difficult to do considering my fatigue and cognitive challenges and symptoms
- I am 100% self-funded by my savings and family, because I have no access to Centrelink or ANY government benefits

3. Diagnosis

- To this date, no Australian medical practitioner has requested I complete an Australian Western Blot or ELISA test
- My current Australian General Practitioners experiencing in treating Lyme disease are using my positive Igenex test results to treat my Lyme-like illness
- I had consultations with approximately 13 Australian doctors, over 88 doctor appointments in just under a 2 year period, without diagnosis for Lyme-like illness (refer to section 2.1 Appointments for further details)
- My American doctor recommended a number of test for me to complete within Australia and in America, which finally diagnosed my Lyme-like illness
- Due to the number of symptoms and infections I currently have, I am constantly being monitored with ongoing and regular (often monthly) testing

3.1 Lyme and Coinfections

I have the following **health related diagnoses** related to **Lyme and Coinfection bacteria and parasites:**

1. Lyme Bacteria: Borrelia (via Igenex Laboratories Western Blot test)
2. Coinfection: Babesia Microti (via Igenex Laboratories)
3. Coinfection: Bartonella Henselae (Applied kinesiology conducted whilst in the US, negative on Igenex test)
4. Coinfection: Rickettsia (Applied kinesiology conducted whilst in the US, negative on Igenex test)
5. An undetermined **parasite** in my stomach
6. *Australian Lab testing for Rickettsia, Ehrlichia, Anaplasma, Sphiliphis, HIV, Brucella, Bordetella have all been negative. No Australian lab is able to test me for Babesia Microti.*
7. *I have never been recommended Bartonella testing in Australia*

3.2 Health Issues

My Health issues caused by Lyme/Coinfections include:

1. **Autoimmune Disease**: Sjogrens Syndrome*
2. **Resistant bacteria in gastrointestinal track**: Kllebsiella oxytoca (US Stool test via Doctors Data Laboratory)
3. **Virus** including recurring Epstein Barr Virus (EBV) also known as Glandular Fever *
4. **Bacteria** including an ongoing Mycoplasma pneumonia* infection
5. **Fungal** overgrowth in the form of candida (not showing on swab tests in Australia, although I have symptoms and physical signs)
6. **Heavy Metal toxicity*** (and US Blood test via Doctors Data Laboratory)
7. **Related health issues** including, Fluctuating thyroid issues*, High Cholesterol*, Liver issues* (previous), Low NK Cells*, these indicate how the immune system is working, Pyrroles*, Vitamin D Deficiency*, Mineral deficiency: Zinc*, Food sensitivities (US electro dermal testing), leaky gut syndrome
8. NOT caused by Lyme/Coinfections, but impacting my ability to heal include Lactose Intolerance^, MTHFR Genetic defects*, Other Genetic SNP defects/mutations (via 23andme laboratory in the US)

* Australian blood test ^ Australian endoscopy test

4. Treatment

4.1 Overview

My treatment overview is as follows:

- There is no ‘one best’ treatment for Lyme-like illness, what works for one person does not necessarily work for another
- The approach to the treatment of my Lyme-like disease is integrative and is guided by my GPs experienced in treating Lyme Disease
- Treatment for my Lyme-like illness started 14 days after diagnoses
- My treatment has been ongoing for 6 months
- My treatment includes and is not limited to:
    - Weekly or twice weekly GP/Integrative Medical Doctor appointments (also covering nutrition and recommended therapies)
    - Regular x-rays, blood, urine, stool tests, physical examinations and other tests
    - Intravenous nutrients and intramuscular injections
    - Medications, antibiotics, antifungals, supplements, herbs, homeopathic treatments, chelation, Lose Dose Immunotherapy, Sublingual Immunotherapy, Nebuliser(for breathing), helminth therapy, heavy metal detoxification/chelation
    - The following allied therapies; acupuncture, lymphatic drainage, chiropractic treatments, exercise physiology & physiotherapy for rehabilitation, colonic hydrotherapy, bio-resonance therapy, lymphatic drainage, laser therapy, floatation tanks, salt room therapy, Rife Therapy
    - Self-administration of exercise, significant dietary changes, Infrared Saunas, Yoga, meditation, coffee enemas, Epsom salt baths
    - In a few months, when my body is ready, I will complete Local Hyperthermia in Australia, at a maximum temperature of 40.5 degrees and utilise a hyperbaric oxygen tank
- My treatments are costing **thousands of dollars each week**!

Note: Details regarding my treatment and therapies have been included I this submission, so as to paint a picture as to the amount of support, financial investment, time and effort is required to gain health from a Lyme-like illness and to indicate that in my ongoing experience, treatment has not been as ‘simple’ as taking medication for 21 days.

4.2 Intravenous (IV) and Intramuscular (IM) Injections

My Intravenous Nutrients (IV) and Intramuscular (IM) Injection details are as follows:

- I go to a clinic 1-2 times per week for intravenous nutrients
- The cost of IVs is extortionately high and ALL out of pocket
- IVs constantly vary and are dependent on symptoms, diagnoses, body capabilities, finances
- Generally I have the following IVs, glutathione (x2), zinc (x2), magnesium (x2), vitamin C, phosphatidylcholine (x *8), sodium bicarbonate
- The veins in my arms are destroyed and my doctors have denied me a PICC line because PICCs are not allowed for nutrients alone
- I have B12 Intramuscular injections several times per week
- I would like to have IV nutrients daily, but am unable to afford this
- My IVs and B12 injections have been one of the most helpful parts of my treatment regime and I notice a significant difference in my heath when I do not have them
- My IVs are costing **$200 to $1600 dollars each week**!

4.3 Medications

My Medication/Supplement details are as follows:

- I take over 50 different medications, injections, supplements on a daily basis
- All of the medications (including antibiotics, antifungals, compounded vitamins and minerals, nebuliser (for breathing) and heavy metal detoxification/chelation), antimicrobial herbs, supplements, homeopathics, Lose Dose Immunotherapy, Sublingual Immunotherapy, helminth therapy have been as equally helpful for my treatment regime – without them, especially the medications and antimicrobial herbs
- I manage the purchase of my medications/supplements from over **20 different suppliers!**
- My medications/supplements need to be taken at over 12 different intervals throughout the day – a very tyring and calculated process between food
- My medications/supplements are costing **hundreds of dollars each week**!

4.4 Outcome

Outcome of my current treatment:

- My health has been improving since the start of my treatment (August 2015) and is trending upwards, although I still have a very long way to regarding my health prior to this illness - some days my health deteriorates as I 'herx'
- As an example, I am still unable to work, concentrate for long periods of time, deal with stressful situations, stand for long periods of time and I require a nap/sleep daily
- As an example, I have had improvement in my energy levels, ability to communicate and process ideas and deal with stressful situations
- I truly believe that with the correct diagnoses and ongoing treatment, I will recover from my Lyme-like disease. I also believe this for other Australians
- I (and many other Lyme-like illness suffers) fear my and other Australian GPs treating Lyme disease will be restricted by the medical board and will stop my treatments which are keeping me alive
- Without the treatment I **have had** up until this point, I truly believe I would be unable to talk and walk today – and would be bed ridden requiring a full time carer
- I am unsure how long I can sustain my current treatment due to the excessive out of pocket expense associate with each of the treatments
- **Without ongoing treatment, my health will decline rapidly. It is unquestionable that my current treatment is keeping me alive**

4.5 Additional Australian treatments

If I had no financial constraints I would access more of the following in Australia:

- Weekly GP/Integrative Medical Doctor appointments and for longer periods of time
- Testing and treatment from the Allergy and Intolerance Clinic in Melbourne for food and other sensitives and allergies
- See a Craniosacral therapist
- Complete Neurofeedback (approx. 3 months at about $20,000)
- Purchase my own person Rife Machine (at a cost of over $4,000) to be used daily
- As the cost of manual therapies is so expensive would have **more** of the following therapies (either daily, several times a week, weekly, monthly etc) acupuncture, lymphatic drainage, chiropractic treatments, exercise physiology & physiotherapy for rehabilitation, colonic hydrotherapy, bio-resonance therapy, laser therapy, floatation tanks, salt room therapy, Rife Therapy
- Have a Faecal Microbial Transplant ($8,000)

- Access additional services for wellbeing/emotional support
- Home help for various things like food shopping and preparation, house cleaning and support services, counting out my weekly medications etc.

4.6 Additional International treatments

Whilst I am working with **three** amazing GPs experienced in treating Lyme disease in Australia and a **fourth** in America, I do not feel that the treatment options available to me in Australia are the world's best, but I am unable to afford further international treatments at this stage. Some of the treatments I would like to have access too but are not available in Australia include:

1. *Canada* - Ty Vincents Low Dose Immuno Therapy for Lyme and other infections, in the form of injections. I currently have these as homeopathics under my tongue, as they are forwarded from my American Doctor.
2. *America* - Seek treatment from Dietrich Klinghardt, MD, PhD (http://www.sophiahi.com/meet-the-team/dietrich-klinghardt-md-phd/) in America
3. *Germany* - Whole body Hyperthermia (over 41 degrees) as per Klinik St. Georg in Germany
4. *Czech Republic* - Visiting a Lyme-like illness clinic whom treat co-infections, such as the BCL – Clinic

5. Impact on my life

I am unable to truly describe or to put in to words just how much this disease has impacted on my life – for the last 2.5 years I have been alive, but not living. Most days I feel like 'the living dead'. When my husband asks me daily how I feel, my reply is generally, 'I feel like a vegetable' or 'I feel like a cabbage', as my brain fog means that I feel like I am in a constant 'vegetative' state.

5.1 Symptoms

I cannot express just how much I have suffered and continue to suffer as a result of living with this disease, but I hope that by sharing *some* of **my symptoms**, this will help to paint a picture as to what I endure:

My **mental capability** is severely impacted the following ways:	Memory loss (short and long term) Confusion, difficulty in thinking Difficulty with concentration (poor) and reading Going to the wrong place Speech difficulty (slurred or slow) Stammering speech Forgetting how to perform simple tasks 'Brain fog'
My **neurological system** is severely impacted the following ways:	Fatigue, Chronic Fatigue Syndrome, weakness Pressure in my head, headaches Numbness in parts of my body, tingling, pinpricks Muscle spasms and twitching Poor balance, dizziness, difficulty walking, stumbling Increased motion sickness Light-headedness, feeling faint, wooziness
My **psychological well-being** is severely impacted the following ways:	Mood swings, irritability Anger outbursts Unusual depression Disorientation (getting and feeling lost) Feeling as if I am losing your mind

My **psychological well-being** is severely impacted the following ways:	Over-emotional reactions, crying easily Insomnia Difficulty sleeping including falling and staying asleep. Tired but unable to sleep Panic attacks and anxiety Paranoia Unaccountable fears Suicidal thoughts
My **head, face and neck** are severely impacted the following ways:	Hair loss Pressure in head Facial paralysis Stiff and painful neck Twitching of facial and other muscles Jaw stiffness Dental problems Sore throat, clearing throat a lot, phlegm, hoarseness
My **general well-being** is severely impacted the following ways:	Phantom smells Unexplained weight gain & loss Extreme fatigue Swollen glands/lymph nodes Unexplained low grade fever and night sweats Continual infections (candida) and colds and flus Symptoms seem to change, come and go Pains and twitching migrate (moves) to different body parts Early on, experienced a ‘flu-like’ illness, after which I have not since felt well Low body temperature Food allergies and food sensitivities Increased effect from alcohol and worse hangover (no longer drink)
My **eyes and vision** are severely impacted the following ways:	Blurry vision Increased floating spots Pain in eyes and swelling around eyes Oversensitivity to light
My **digestive and excretory systems** are severely impacted the following ways:	Constipation Irritable bladder Upset stomach
My **musculoskeletal system** is severely impacted the following ways:	Stiffness of joints, back, neck, tennis elbow Joint pains
My **respiratory and circulatory systems** are severely impacted the following ways:	Shortness of breath, can’t get full/satisfying breath Chronic cough Night sweats/unexplained chills Heart palpitations and extra beats

5.2 Key areas of my life

All of the symptoms I experience are real - some days the symptoms are more pronounced than others and the symptoms come and go – either way, every day I have at least one symptom. I feel like I am living a *nightmare* that I am never going to get away from or wake up from. But these *'are just symptoms'*, right? This is just how I 'feel' … To demonstrate how **my day to day life has been impacted** by this disease, I will take you on a journey of how I was living my life before my illness and how I have been forced to live my so-called life during my illness, covering the key areas of '**life**' including **work, fitness, finances, diet, sleep, mobility, socialisation, entertainment, transport, speech, physical and relaxation**.

	Before my illness	**During my illness / my current 'life'**
Work	• Employed in a corporate role as an IT Project Manager/Trainer working 40+ hours a week • Employee of the Year and Outstanding Achievement of the year, 2 months prior to illness onset	• Unable to work in any capacity as unable to focus on a task for more than a few seconds or minutes as well as excessive anxiety and memory loss
Fitness	• 60km+ cycle/wk • 5-7 x Boot camp sessions/wk • 2 x PT sessions/wk	• Unable to exercise (all forms) • Unable to walk 300 metres* • Unable to complete a stretching class due to body fatigue*
Finances	• Able to bring in an income to support me and my family	• Unable to bring in any income to support me and my family • Excessive spending on health and wellness • Unable to claim any Centrelink payments or Health Care card
Diet	• Wine and dine at various restaurants several times per week • Able to eat all types of foods without reaction	• Restrictive diet due to severe food sensitivities and impact on disease recovery • 90% of food must be home-made by me • Unable to eat out at restaurants due to extensive food restrictions • Unable to drink or tolerate alcohol • Organic, wild caught, grass fed produce required • Free from dairy, grains, sugar (including all fruit and natural sweeteners such as honey), alcohol, nightshades, soy, corn, and additional vegetables I am now sensitive to • Low carbohydrate (including no fruit) • Free of processed food, additives, colours
Sleep	• Able to sleep solidly	• Awake 2-6 (or even 20) times per night to urinate • Nightmares • Often wake up screaming • Insomnia and anxiety (tired by wired)
Mobility	• Highly mobile	• Unable to walk 3-5 steps without having to stop – loss of energy and breath*
Socialisation	• No restrictions on socialising	• Unable to attend social gatherings and events due to symptoms and fatigue • Unable to talk and communicate*
Entertainment	• Watch TV • Listen to music • Read books	• Unable to watch any TV due to sensory issues* • Unable to listen to music of any kind at any volume* • Unable to read due to memory loss and concentration*

Transport / Driving	• Proficient driver with no accident history • Drive with music and have conversations on speaker phone	• Had car accident • Unable to drive with any sound or talk on phone • Often leave car unlocked • Has left car unlocked with keys in ignition • Sensory processing issues when driving and need to drive very slowly
Speech and Physical	• Converse at fast pace	• Unable to speak, find words, interact in conversation, unable to finish sentences or express thoughts*
Relaxation	• 3 x yoga sessions per/wk • Thi Chi & Chi gong	• Unable to attend a Yoga class, or do Tai Chi or Chi Gong due to fatigue* • Challenges meditating due to anxiety*

* Until recently

5.3 My Story

Whilst I am not my illness, it has and continues to affect me in ways even I find it hard to explain and understand, as my cognition is extremely affected in so many ways I am unable to control or understand. I have been in a very scary and dark place. I have been depressed beyond belief and had suicidal thoughts (something I have never experienced before). I have struggled with my thoughts and my life, as well as grieving the parts of my life I have lost to this wretched illness. I have called out for help – but often no one has been there to hear my calls.

I have lost my independence, my ability to leave my bedroom and I have barely left my house, except for treatments and food supplies.

I have been sick beyond words (and understanding) for a very long time. For over 6 months whilst still working, I gave every inch of my being to doing everything in my power to continue to work and contribute to my family. Do you know what it's like to be so ill that you can't shower, or walk a few metres, or prepare a meal for yourself when every inch of your body wants to rest? I have been in this state - on empty - and pushed myself every day. I cried hysterically to myself daily. I was pushing beyond my limits. Amongst other things my cognition deteriorated significantly – often I had an attention span of a few seconds to a few minutes. I would walk in and out of the house before work 6 times to 'check' I hadn't left the gas on, because I had forgotten what I had did 30 seconds ago. I nearly had several car accidents on a daily basis to and from work due to my memory loss. My head and brain has constantly ached and had a pressure like it was about to exploded … It affects my facial features too - my ability to smile, and has resulted in me frowning or a look of anger on my face that I can't control. I could not process many basic concepts, ideas and interactions. I have been in a hysterical and desperate state – many a days I have struggled to hold on.

"I have been unable to walk, talk, smell, hear, see, taste and breathe – all in the one day.
I feel like a vegetable, a cabbage.
I am living a nightmare I feel I will never wake from.
My pressure in my head feels like it is about to explode.
I am alive, but I am not living.
Please, please please!
I beg you to help me and my fellow Australians!
YOU have the power to help me and my fellow Australians!
YOU have the power to put a stop to the suffering
I just want my health back … I know it IS possible with treatment and YOUR support
I want more than anything in the world to be well"

January 2016

5.4 My Husband

- For the last 2.5 years, my husband sleeps in our spare room, because I walk up screaming, tossing and turning
- I have been highly sensitive to light, sound and touch (not even my husband could touch or hug me at times)
- He gets up early for work, comes home late and works on the weekends to support me and to support us
- My husband and I don't kiss because I am riddled with contagious bugs such as candida, streptococcus and mycoplasma pneumonia (just to name a few), which he has contracted from me resulting in time off work and further medical expenses
- **He needs to be tested for Lyme-like illness but the $2000 price tag for the Igenex Australian Lyme Panel 3 is outside of our reach and so is the treatment, if required**

5.5 Family

- My family do not fully comprehend what I am going through
- One of the saddest parts of my life impacted by this disease has been missing the birth and first 3 months of my first nephew's life. I have only seen him a hand full of times over 18 months due to my illness as was not able to see him for the first three months of his life
- One of my family members no longer talks to me and refuses to have me in their life, due to how my Lyme-like illness has affected me and my cognition and behaviour, significantly changing the person I am

5.6 Friends

- For 2 years I was unable to socialise, return phone calls, SMS, write emails, and at many times and talk to my friends. I have many old relationships which have not survived my illness

5.7 Lyme-like illness suffering friends

- I am in contact with over 100 Lyme-like illness suffers in Australia
- 5 of my friends with Lyme-like illness experienced seizures in the last 14 days! 2 of these 5 friends were admitted to hospital
- At time of writing, one of my friends has just been denied ambulance collection and admission to hospital because they have Lyme-like illness
- I can't even begin to describe the suffering I see my friends experience on a daily basis – it is just heart breaking

5.8 My Financial Costs

The **financial impact and costs** of trying to survive and overcome Lyme-like disease is and continues to be devastating for me and my family:

- Lyme-like disease is an 'illness for the rich'
- The cost to the point of diagnoses was thousands and thousands of dollars, this does not include the lost income from my lack of ability to work
- I travelled to the US in August 2015 to see my Doctor for 1 week at great financial cost
- The cost for treatments and medications that are keeping me alive is hundreds and thousands of dollars every week
- Very few tests, medical appointments, medications, tests, supplements and treatments have been covered by Medicare. I would estimate that over 95% of expenses are out of pocket for me
- The average Australian and 99% of Australians are not able to afford these treatments
- I know one Australian who lives on $10 a week for ALL treatments and medications

- I am not entitled to Centrelink or any other benefits (except 5 Allied Health sessions per year, which I can utilise within 1-2 weeks of treatment)
- A 21-day prescription of Wellvone (Atovoquone), cost me $1,100! That calculates to be $26 per teaspoon or $52 per day. This medication is utilised internationally for Babesia. It is not available via PBS for Babesia in Australia. It is accessible to Australians with other conditions at a cost of $38 through Medicare/ Pharmaceutical benefits Scheme (PBS)
- An hour appointment with GP experienced in treatmenting Lyme disease can cost from $280 per hour to $750 per hour
- The cost of one Intravenous sessions can cost anywhere from $300 per session to $800 per session including the cost of the Doctor/Nurse and the medications
- On average, the weekly cost of my treatment is thousands of dollars per week
- **I don't know how long I can continue to afford to keep up my treatments and medical bills as the weekly cost is exorbitant. Although without the treatments, my health WILL decline**
- Early diagnosis would have saved the Government thousands of dollars

5.9 My future

The symptoms I experience as a result of my Lyme/Lyme-like disease are many and varied and they have and continue to, severely impact my ability to live my life to the fullest.

Due to the challenges and suffering I have experience and have seen others experience, and although I am not yet well enough myself, I have started to give back to other Australians with Lyme-like illness including:

- Facilitating a Lyme disease support group
- Directing and managing a Lyme support and community Facebook page
- Volunteering with the Lyme Disease Association of Australia

I have positive hopes for the future, that my health will continue to improve and that I will be able to live a life somewhat like I used to. I dream of being able to ride my bike across the Harbour Bridge, go on holidays and ski trips, hug my husband without pain, listen to music, watch television, think normally, eat and drink wine like I used to, sleep soundly and also study and work at my previous capacity.

My future will involve helping and supporting Australians with Lyme-like illness and helping to get this horrendous disease recognised.

6. Future Outcomes of the Inquiry

Based on my personal experience and my interaction with many patients with Lyme-like illness and their journeys and suffering, I would like to see the Inquiry address, implement and review the following as a minimum:

6.1 Inquiry Process

As a minimum, I would like the Inquiry to:

- Speak and meet with ALL of the Australian GPs who are treating Lyme-like illness in Australia
- Spend a significant amount of time at with patients suffering from Lyme-like illness (many of whom will be too unwell to travel)
- Spend a significant amount of time in the Australian IV clinics where Lyme-like patients seek treatment
- Actively contact and speak with vets, school teachers, principals, doctors, specialists and outdoor workers (private and government workers from councils, state, federal organisations), especially

those in endemic tick areas (such as Central Coast/Hunter Valley region and Sydney's Northern beaches)
- Review existing International Acute and Chronic Lyme-like illness diagnostic and treatment protocols
- Significantly engaged the Lyme Disease Association of Australia, who are one of the key organisations within Australia who understand and have access to Australians with Lyme-like illness
- NOT judge the Senate Inquiry based on the limited number of individual patient submissions who have contributed to the Inquiry. It is imperative that further information be gathered about patients affected, as there are thousands of innocent Australians like me, who are stuck down by this disease and are struggling with their day-to-day life, trying to survive and stay alive – many of whom are not well enough to contribute to this Inquiry.

6.2 Inquiry Outcomes

As a minimum I would like the following **outcomes** from the Inquiry:

Immediate action **must** be taken by the Government with regards to recognition of Lyme/Lyme-Like Disease in Australia and the subsequent pathology, diagnosis, education, support, awareness and treatment must support this recognition.

Once Lyme-like disease and coinfections are recognised within Australia, I would like to see the following implemented **immediately**, to assist and support suffering patients and their families:

6.2.1 Practitioners;

a. Immediate and ongoing protection for ALL current treating practitioners
b. Immediate and ongoing review of ALL treating practitioners who have been put on restriction
c. Immediate and ongoing protection for ALL current treating practitioners who are currently utilising overseas treatment guidelines and are having treatment success
d. Full support of the medical community providing the treating practitioners
e. All GPs to be trained in tick-removal, acute and chronic Lyme-like illness diagnostics, symptom interpretation and treatments
f. Training for doctors to specialise in Chronic Lyme-like illness management
g. **Consideration:** Due to the experiences, trauma, fear, disillusionment and disrespect patients have for the majority of medical doctors, significant review and consideration **must** be given when deciding which practitioners will be best to support patients in the future. Due to the holistic and long term nature of the disease, practitioners who specialise in long term care of Lyme/Lyme-Like Disease and coinfections may be best to support these patients

6.2.2 Implementation of Lyme-like illness data collection and existing patient review

h. Capturing of data by GPs, hospitals and specialists etc.
i. Additionally, an online method of data collection accessible to all Australians
j. I would like to see all patients diagnosed like Multiple Sclerosis, Chronic Fatigue Syndrome, Parkinson's Syndrome, Sjogren's Syndrome, Fibromyalgia, Motor Neurone disease, Rheumatoid Arthritis, Alzheimer's, Hashimoto's disease and ADHD/ADD/Autism and other behaviours disorders and autoimmune disease be re-assessed for tick and other vector-borne diseases

6.2.3 Prevent and stop the transfer of Lyme-like illness through;

k. Action preventing anyone with Lyme/Lyme-Like disease and coinfections from **donating organs** and **blood**, so as to prevent the transfer of these diseases via organ and blood screening of and potentially testing of, all potential organ and blood donors who have been bitten by a tick (as a minimum) and possibly other vectors. Additionally, free Lyme/Lyme-like disease and coinfections testing made available to **ALL persons** (irrespective of symptoms) who have received organ donations and blood in the past

l. Education campaigns regarding preventing **sexual transmission** of these diseases

m. Education campaigns regarding how this can be passed on **in utero**, so as to limit children being born with these diseases and suffering unnecessarily

6.2.4 Educational and patient support;

a. **Through a fully funded National support program and education campaign** covering prevention, tick/vector removal methods and Acute and Chronic Lyme/Lyme-like disease and coinfection management

b. **Provide Government funding to the Lyme Disease Association of Australia**, so as that this educational and support service can be run with paid and fulltime staff, as it is currently run by volunteers, generally whom have or have been touched by Lyme disease

c. **A support and reporting hotline**: A critical tool required within Australia following disease recognition. The hotline could focus on four key areas of information: support, education and awareness (as per the LDAA) as well as become a key reporting tool on the potential impact of the disease within Australia. This hotline/support tool could also facilitate and support patients in reporting practitioners who continue to deny them Lyme/Lyme-like treatment, deny they have Lyme, ridiculed etc. This aspect is important so as to ensure patients receive appropriate treatment once recognition is established. Hotline also to be available for emergency educational and support for tick removal

d. **Education campaigns for people and industries highly susceptible to ticks and other vectors known to transport Lyme-like illness**, such as outdoor workers, including and not limited to council workers, National Parks and Wildlife workers, vets, people working with animals, landscapers, gardeners, forestry services etc.

e. Educational campaigns for all **Australians travelling internationally**, especially those travelling in endemic areas (but not limited too)

6.2.5 Acute and Chronic Treatment of Lyme-like illness;

f. Acknowledgement that there is no 'one best treatment' method is imperative in the process, so patients have the right to choose how to heal from this disease, which can include antibiotics (oral and IV), medications, natural herbs, supplements and IV nutrients etc. combined with manual therapies and supporting services

g. Affordable, timely, appropriate, accessible diagnostics and treatments made available for **ALL** Australians for Acute Lyme-like illness

h. Design and implement a world's best practice nation-wide diagnostic and treatment protocol, to be implemented by ALL doctors and allied health professionals for the Acute and Chronic treatment of Lyme-like illness that has been designed in consultation with a review of existing international protocols

i. For all Lyme-like illness medications to be affordable, timely, appropriate to ALL Australia's with Lyme-like illness including and not limited too:

    i. Meprone / Wellvone / Atovoquone (antibiotics)
    ii. Azithromycin (antibiotics)
    iii. Cannabis oil
    iv. Intravenous Nutrients and Medications:
        1. Intravenous Nutrients including and not limited to Vitamin C, Folinic Acid, Zinc, Magnesium, B Vitamins, Phosphatidal Choline, Sodium Bicarbonate, Calcium, Glutathione made available through Medicare / rebates
    v. Dr Zhangs Herbs for Lyme-Like illness

  - vi. Low Dose Immune Therapy for Lyme disease to be made available in Australia http://www.ingelsfamilyhealth.com/category/low-dose-immunotherapy-ldi/

Note: this is a very limited list of potential medications

- j. With regards to the administration of medications and/or nutrients via PICC/Port
  - i. Review existing guidelines for Lyme-like illness patient administration of medications and/or nutrients via PICC/Port, so as patient choice is not restricted/limited to catheters, when a PICC/Port may be more appropriate
  - ii. Public health community nursing services to support PICC line dressings/medication administration

6.2.6 Diagnostics;

- k. Implementation of the following testing principles with regards to Lyme-like illness AND **coinfections and a designed protocol including:**
  - i. Local (i.e. accessible in Australia)
  - ii. Accurate (i.e. includes ALL related coinfections)
  - iii. Affordable (no out of pocket expense for patient)
  - iv. Timely (**all** possible coinfection testing completed at the time of Lyme/Borrellia testing)
  - v. Regular (patients to be able to be retested for Lyme and coinfections within defined intervals, i.e. 6 months covered under Medicare)
  - vi. Associated testing (thyroid, liver function, white/red bloods, Lipids, minerals, in-depth stool testing, genetic testing (i.e through 23andme), urine testing for heavy metals, organic acid tests for nutritional and metabolic information, allergy related/food sensitivity etc) covered by Medicare and enabled to be accessed monthly
- l. **Diagnostics for partners, bloodline and live-in family members once a positive reading is returned for one family member:**
  As Lyme/Lyme-like/vector borne disease and many coinfections can be orally transmitted (such as mycoplasma phenomena, streptococcus and glandular fever/Epstein-Barr virus) and sexually transmitted (such as Borellia), past and represent partners and family members (i.e. bloodline and live-in children) must be made accessible to comprehensible Lyme/Lyme-like/vector borne disease testing upon immediate diagnose of a person with Chronic Lyme disease and/or those currently with Chronic Lyme disease

6.2.7 Financial Support;

- m. Pharmaceutical Benefits Scheme:
  - i. An extensive **review of the medications available** for Lyme/Lyme-Like Disease patients, under the PBS. As per example above relating to the $1000+ cost of 21 days of Wellvone (Atovoquone)
  - ii. An inclusion of **supplements, vitamins, minerals and homeopathics** for patients, as these are required in addition to antibiotics
  - iii. **Compounded medication** to be included/subsidised under the PBS
  - iv. **Intravenous Nutrients** to be included/subsidised under the PBS
- n. Medicare:
  - i. Significantly increase the number of days accessible for patients under the **Mental Health Care Plan**, as the current 6-10 days is nowhere near adequate

   ii. Significantly increase the number of days and services accessible for patients under the **Allied Health Services** section, as 5 sessions nowhere need adequate
   iii. Cover and support additional **Allied Health Care Services**, including Alternative Therapies such as Applied Kinesiology, Massage, Acupuncture, Naturopathy and Nutrition etc
   iv. Patients in regional areas able to **claim travel under IPTAS** (isolated patients travel and accommodation scheme)
   v. **Remote (Skype/telephone) appointments** to be covered under Medicare – as many patients are too unwell to travel
   vi. Review other areas where subsidies can be provided for those with Lyme-like illness

o. **Centrelink**: All patients diagnosed with Lyme/Lyme-Like disease and coinfections that unable to work, must be immediately **enabled to access the Centrelink Disability support and a Health Card**, irrelevant of means testing

p. **Insurance companies**: Recognition of Lyme-like illness by private health funds

6.2.8 Science & Research;

Continue and invest significantly in research of Lyme-like disease in Australia without compromising patients who require immediate care and support

6.2.9 Explore the concept of new diseases

New diseases are discovered every day, and HIV/AIDS, Zika virus, Avian influenza (bird flu) are some examples of a few disease that have recently been discovered. Diseases are discovered because people become ill, suffer and some result in death. Research, funding, medications, trials, training, education, prevention and awareness are all implemented by governments to prevent further transmission and spread of diseases, so as to prevent pain, suffering and death.

Lyme-like illness is a disease in which Australians are becoming ill, suffering and dying. This disease must be explored like any other disease, and give adequate funding and immediate priority for review.

6.3 Current Medical Process – current treatment of Lyme-like illness

Irrespective of the Senate Inquiry, Lyme-like patients must receive the same treatment as patients with other illnesses in Australia as per the current medical process.

To explain the current medical process in simplistic layman's terms, an example of a person with 'painful' stomach symptoms or a sore throat is presented below.

Currently, when an Australian is unwell, they may present to a GP or specialist with a number of symptoms such as a 'painful' stomach or a sore throat. The doctor may examine them and make a diagnosis based on described symptoms, often without detailed laboratory testing. Patients are not refused or denied treatment of their 'painful' stomach or sore throat because their condition is not 100% defined by tests or 'recognised'– often these are not ordered.

As per the example provided, patients ARE treated and often this IS based on symptoms. Patients with Lyme-like illness MUST be given the same basic right as all other Australian patients IMMEDIATELY – to be treated based on their symptoms as well as with positive Lyme-like illness test results from international laboratories.

7. Conclusion

Upon reflection of my submission, you ‘may’ be tempted to think that the detail, articulation and length of this document does not reflect that of what someone who is ‘sick’ and has cognitive issues including excessive brain fog and memory loss, is capable of writing. Let me reassure you, that up until a few weeks ago, I was not capable of writing more than a few sentences – definitely not a letter of this length. The last few days alone has seen my cognition improve dramatically, enabling me to write such a detailed response. It is also an indication that with treatment I am capable of great things. This submission has taken me in excess of 25 sessions and approximately 40 hours to write.

In conclusion, some of the **key and basic facts** are that:

- I am proof that Lyme-like illness DOES exist in Australia
- Australians, including those who have and have not travelled within the country AND those who have travelled abroad ARE sick from Lyme-like illness
- It is time to stop debating whether Australian ticks have bacteria that are making Australians sick, and focus on treating sick Australians!
- Early diagnosis and treatment WILL SAVE the government thousands of dollars every year
- NO Australian should be denied testing and treatment for this disease, even if Australian diagnostic tools are not available yet – existing internationally testing and treatments MUST be made available in Australia
- NO Australian should have to consult an international doctor for testing, diagnosis, medications or treatments in relation to Lyme-like illness
- NO Australian should have to spend in excess of $2000 out of pocket for a Lyme-like illness test (i.e. Igenex)
- NO Australian should have to travel overseas for testing, diagnoses or treatment for their Lyme-like illness
- NO Australian should be denied access to medications or treatments for Lyme-like illness
- NO Australian should have to experience the current out-of-pocket expense that current Lyme-like illness suffers experience
- NO Australian with Lyme-like illness should have to be over $20,000 out of pocket and travel overseas for hyperthermia, one well known and often effective option for the treatment of Lyme/Borrelia Burgdorferi
- NO Australian with Lyme-like illness should be told by any Australian practitioner that their Lyme-like illness does not exist
- Unlike like some cancers, heart disease, diabetes, obesity etc. Lyme-like illness is NOT a disease that is caused by diet and lifestyle factors
- NO Australian should have to experience 88 doctor appointments/13 doctors before reaching a diagnosis of Lyme-Like illness
- NO Australian should have to encounter over 50 tests for a diagnosis of Lyme-like illness
- NO Australian should have to wait 2 years or more for a diagnosis of Lyme-like illness
- NO Australia should be denied access to a hospital because they have Lyme-like illness
- NO Australian should be humiliated, discriminated against or vilified because they have Lyme-like illness
- NO Australian should be denied that Lyme-like illness does exist by their Government

This is my Lyme-like illness story and journey and it is my wish that no other Australian experience the nightmare that I have and continue to experience. Sadly I know too many Australians who are currently suffering from this disease and all its facets. Every day is a challenge for Lyme/Lyme-like disease patients and their families, including me and mine.

I loved life before I became ill and I am doing everything in my control to regain my health, wellness and life back – but there is a lot outside of my control that YOU, the government have the ability to change.

Lyme-like disease sufferers such as myself are innocent and we just need and want your support in getting better, so we can live our lives to the fullest and get back to contributing to Australian society again.

Thank you for the opportunity to make a submission to the Inquiry. I look forward to hearing about the recommendations, outcomes and positive changes brought about by the Senate Inquiry.

Please feel free to contact me at any time to discuss my submission further or to speak with the committee.

Yours Sincerely,