Patient submission

Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients

Janice Foster

2016

Table of Contents

Summary

My name is Janice Foster, and I am 41 years old.

As a patient with a Lyme-like illness, I am publicly sharing my story in the hope of providing insight into the pain and distress caused by my condition, the humiliation many patients have faced at the hands of medical practitioners, the ongoing lack of appropriate response from government authorities and the isolation from the general community resulting from this.

This document covers background information regarding myself to ensure credibility, an account of my decade-long search for a diagnosis, my subsequent treatment journey and the role 'Lyme literate' doctors (LLMDs) have played in this.

In addition, I have shared stories regarding other patients that I was personally involved in; these stories demonstrate the negative impact the government's lack of respectful and decisive action regarding Lyme-like illness has had on the conduct of hospital employees, and the traumatic consequences for patients.

I have also included a detailed breakdown of the ways in which the government's response to this situation has been wholly inadequate from my perspective, and the flow on effects of this to the medical community, media, general community, and patients' interpersonal relationships.

This document then focuses specifically on what my life looks like today, and what the personal impacts of my experiences as a Lyme patient have been.

Finally, I have made some recommendations of avenues of investigation for the Senate's consideration.

Please note that for convenience, I have generally referred to the condition I have throughout this document as 'Lyme', although I fully accept that it's very likely a variation of Lyme, or possibly a completely different bacterial infection with similar devastating symptoms.

Thank you for reading my submission; after being voiceless for so many years, the opportunity to be heard is very precious to me. I hope that you are able to approach this document with an open mind and a willingness to place yourself in my shoes, and the shoes of other patients and our supporters. It's not an easy place to be.

"Courage is what it takes to stand up and speak; courage is what it takes to sit down and listen".
- Winston Churchill

About me

Unfortunately, doubt is often cast on the validity of claims made by people whose symptoms are not immediately indicative of a widely recognised, or easily diagnosed, medical condition. They are often assumed to be lying for attention, suffering from a form of mental illness, or simply too lazy to want to participate in society as is expected.

For that reason, credibility is a crucial part of the battle for Lyme recognition. I hope that you will indulge me by taking the time to read some evidence I'd like to present regarding my character, the circumstances I was experiencing at the time I became ill, and my circumstances when I eventually stopped working, 10.5 years into my illness.

Firstly, I’ve certainly never had a need to create any drama or ‘sob stories’ for attention or sympathy. Like many people, my life hasn’t been smooth sailing. The most prominent example of this is the suicide of my 17yo brother, when I was 13yo, in 1988.

Given that removing the stigma of mental illness and suicide has only relatively recently become a focus of the media and the general community, you can imagine how difficult it was for me as a young teenager to deal with not only my grief, but the lack of support available almost 30 years ago.

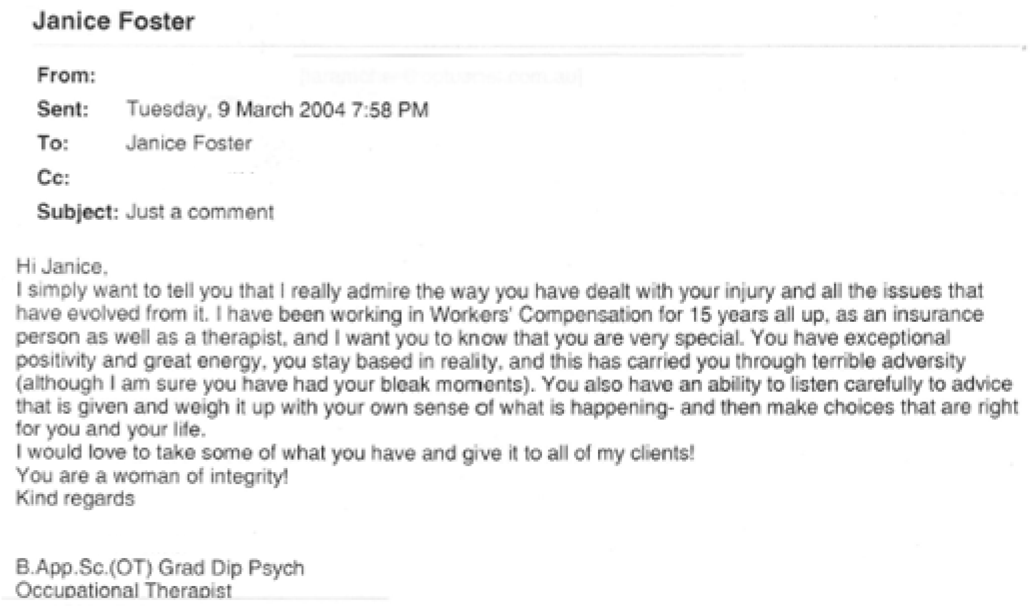
As a result, I struggled with depression right into my early 20s.

Had I wanted attention or sympathy, I presume I would have been able to get them based on these experiences, without the need to invent an illness. Instead, I simply sought counselling to work things through, and years later jumped at the chance to volunteer for WINGS of Hope, a charity for people bereaved by suicide.

The other prominent negative event in my life is the assault I experienced on my way home from work at [suburb redacted], on 27 October, 2003. While walking to my car, I was attacked from behind, in what police believe was *“a bag snatch gone wrong”.* My skull was fractured, resulting in a moderate head injury that took years to recover from, and the permanent loss of my senses of smell and taste.

Again, an opportunity presented itself for me to revel in attention, if I so desired, but I did not. In fact, some of my work colleagues commented on my lack of emotional outpouring at the time, saying that I was “*like a robot*”. (Actually, at the time I was already 18 months into my Lyme experience, and was very much in a “when you’re going through hell, keep going” mindset; I couldn’t afford the indulgence of falling apart.)

The Occupational Therapist assigned to my case saw things differently from those colleagues, as per the below email:



Janice Foster

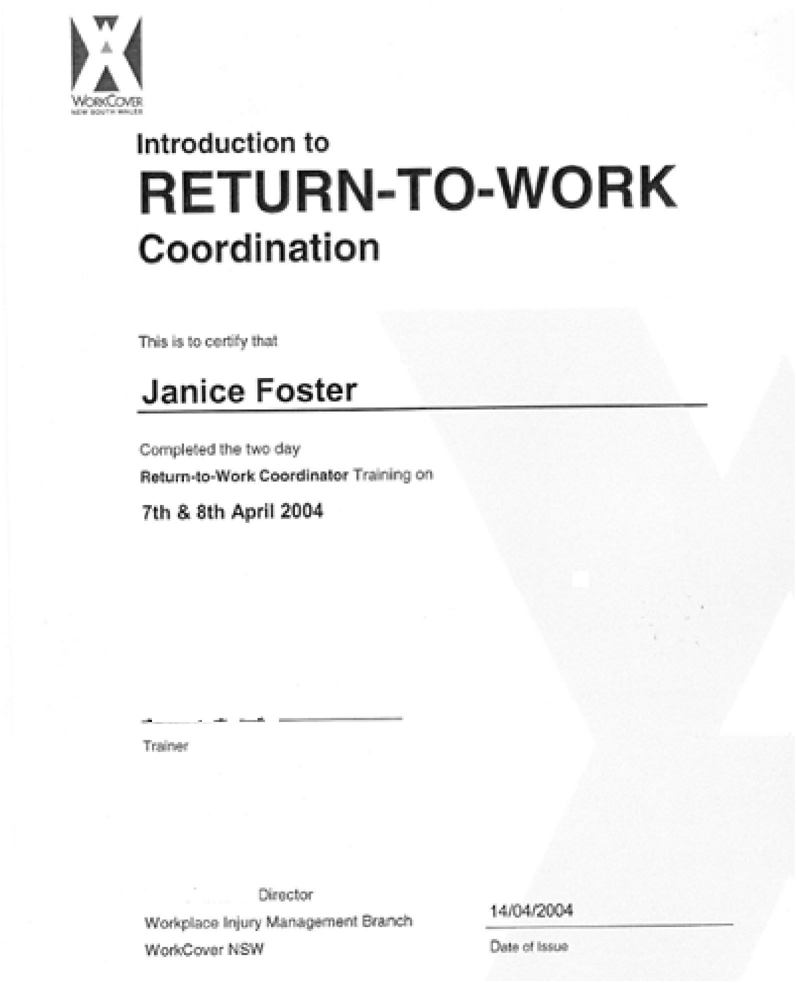
From:
Sent: Tuesday, 9 March 2004 7:58 PM
To: Janice Foster
Cc:
Subject: Just a comment

Hi Janice,
I simply want to tell you that I really admire the way you have dealt with your injury and all the issues that have evolved from it. I have been working in Workers' Compensation for 15 years all up, as an insurance person as well as a therapist, and I want you to know that you are very special. You have exceptional positivity and great energy, you stay based in reality, and this has carried you through terrible adversity (although I am sure you have had your bleak moments). You also have an ability to listen carefully to advice that is given and weigh it up with your own sense of what is happening- and then make choices that are right for you and your life.
I would love to take some of what you have and give it to all of my clients!
You are a woman of integrity!
Kind regards

B.App.Sc.(OT) Grad Dip Psych
Occupational Therapist

My manager at the time agreed, and nominated me to undergo Workcover training to become the Return To Work coordinator for his call centre of approximately 100 staff.

I completed this training a month later, and worked successfully to integrate employees back into the workplace after injury, providing both emotional and practical support.



WorkCover

Introduction to
RETURN-TO-WORK
Coordination

This is to certify that

Janice Foster

Completed the two day
Return-to-Work Coordinator Training on
7th & 8th April 2004

Trainer

Director
Workplace Injury Management Branch
WorkCover NSW

14/04/2004
Date of Issue

I hope these examples are sufficient in illustrating my lack of interest in seeking attention for attention's sake.

In addition to addressing my character, I'd like to cover the circumstances of my life at the time both when I first became ill, and when I was finally forced to give up paid employment 10.5 years later.

When I became ill in early 2002, I was enjoying the best period of my life. I loved my job as a Team Leader in a call centre, and I was very good at it – I wish I had kept my performance reviews and awards as proof, but unfortunately I threw them out because in the years to follow, the reminder of how good things had been was too painful for me.

What my employers can probably verify is that around this time I had won a major award, with a $5000 travel voucher as the prize. As my father had grown up in the Depression era (he was in his late 40s when I was born), he had a frugal approach to finances, and the family had never gone on holiday. His influence had rubbed off on me, so I was very much looking forward to using the voucher to travel overseas for the first time, and to share the experience with my boyfriend of six months (who is now my husband), Ryan.

I was very happy, so much so that one of my staff nicknamed me 'Budgie', saying I was "small and chirpy, flittering around talking to everyone."

So it was a very exciting time, and all areas of my life were going well – there was no reason for me to either pretend to be sick, or to actually become physically sick as a result of any severe emotional stress.

When I finally gave up work in October 2012, after more than a decade of battling chronic illness, I was understandably feeling much less chirpy, but was still very much engaged in the world and unwilling to give up. I have included below the most prominent parts of my last Performance Development Review in my role as a Business Analyst, to demonstrate that I was still a dedicated employee who had no desire to give up work.

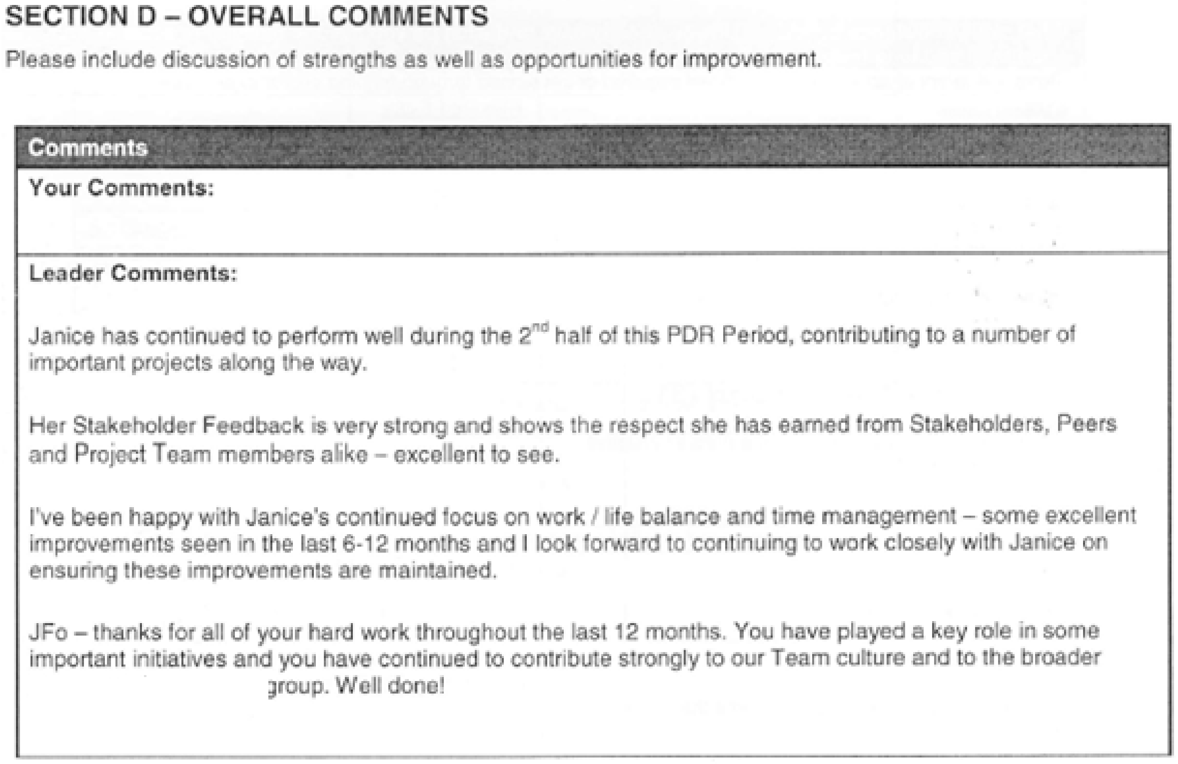
As Lyme deniers often assume patients are gullible people vulnerable to the power of suggestion, I would like to point out that critical thinking is a key skill in the Business Analyst role.

You'll notice in the 'Leader Comments' section, my manager has referred to my "*continued focus on work/life balance*". This is in relation to the very long hours I had a habit of working – as you can imagine, for a manager in a corporate environment to actually ask an employee to reduce their working hours, it was pretty excessive! I am certainly not someone who was looking for an excuse to sit around home all day.

(There are several reasons for my work/life imbalance, incidentally; firstly, there are frequent redundancies in the fast-moving telecommunications industry, and I didn't want to be in consideration for one, as I was so mentally and physically fatigued that I couldn't imagine I'd be able to muster up the energy for the steep learning curve required to start a new job at a new company.

Secondly, I never gave up hope that the cause of my illness would be discovered, and assumed that given how long it took to diagnose, the treatment would probably be expensive, and very possibly not be available in Australia. So I needed as many big performance bonuses as possible in order to have the funds ready for that treatment.

And finally, by that stage I felt I had so little control over my life - my body, relationships and future direction - that I got some pleasure from being able to have a measurable impact on something.)



SECTION D – OVERALL COMMENTS

Please include discussion of strengths as well as opportunities for improvement.

Comments

Your Comments:

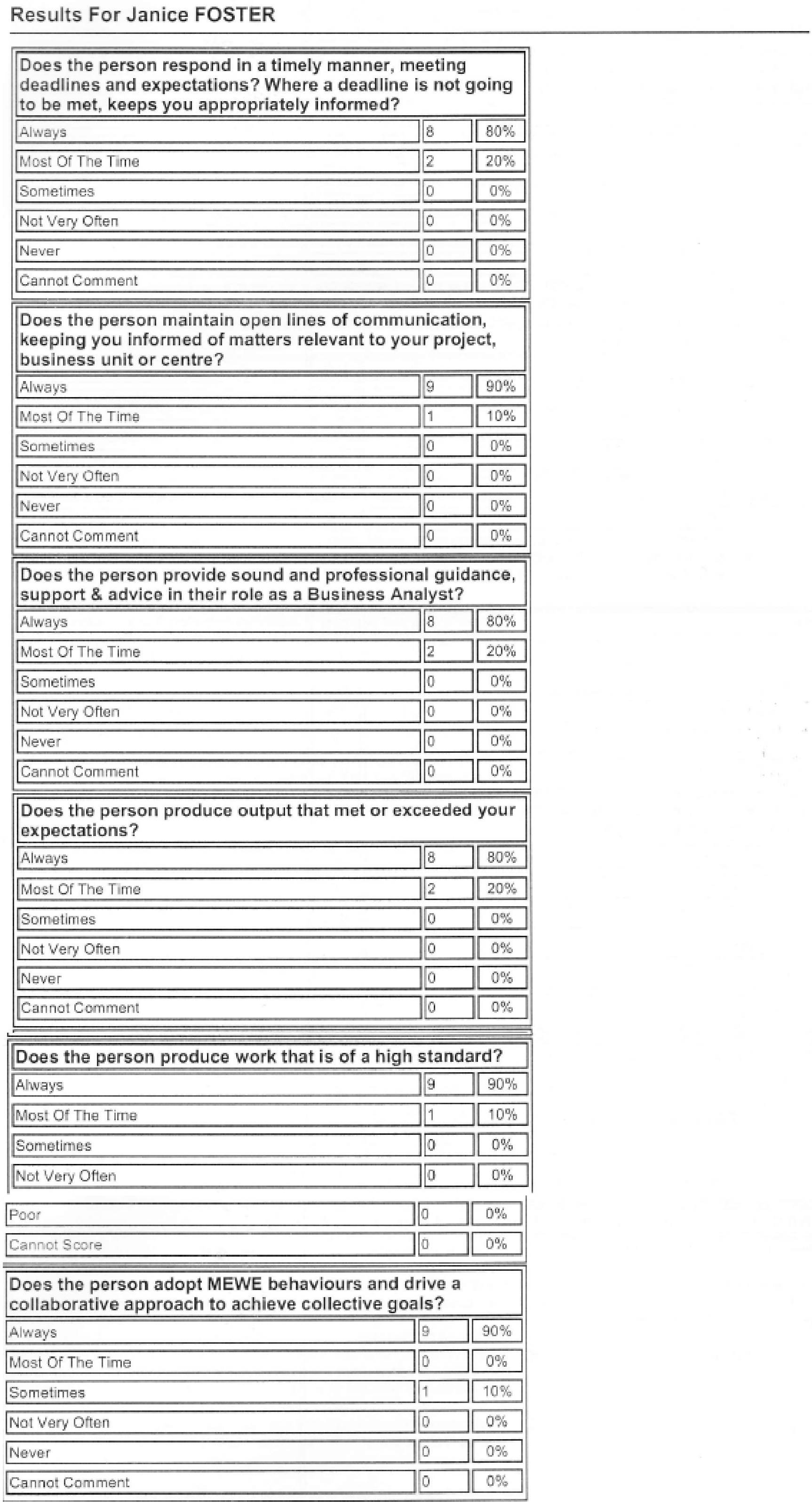
Leader Comments:

Janice has continued to perform well during the 2nd half of this PDR Period, contributing to a number of important projects along the way.

Her Stakeholder Feedback is very strong and shows the respect she has earned from Stakeholders, Peers and Project Team members alike – excellent to see.

I've been happy with Janice's continued focus on work / life balance and time management – some excellent improvements seen in the last 6-12 months and I look forward to continuing to work closely with Janice on ensuring these improvements are maintained.

JFo – thanks for all of your hard work throughout the last 12 months. You have played a key role in some important initiatives and you have continued to contribute strongly to our Team culture and to the broader group. Well done!



Results For Janice FOSTER

Does the person respond in a timely manner, meeting deadlines and expectations? Where a deadline is not going to be met, keeps you appropriately informed?

Always	8	80%
Most Of The Time	2	20%
Sometimes	0	0%
Not Very Often	0	0%
Never	0	0%
Cannot Comment	0	0%

Does the person maintain open lines of communication, keeping you informed of matters relevant to your project, business unit or centre?

Always	9	90%
Most Of The Time	1	10%
Sometimes	0	0%
Not Very Often	0	0%
Never	0	0%
Cannot Comment	0	0%

Does the person provide sound and professional guidance, support & advice in their role as a Business Analyst?

Always	8	80%
Most Of The Time	2	20%
Sometimes	0	0%
Not Very Often	0	0%
Never	0	0%
Cannot Comment	0	0%

Does the person produce output that met or exceeded your expectations?

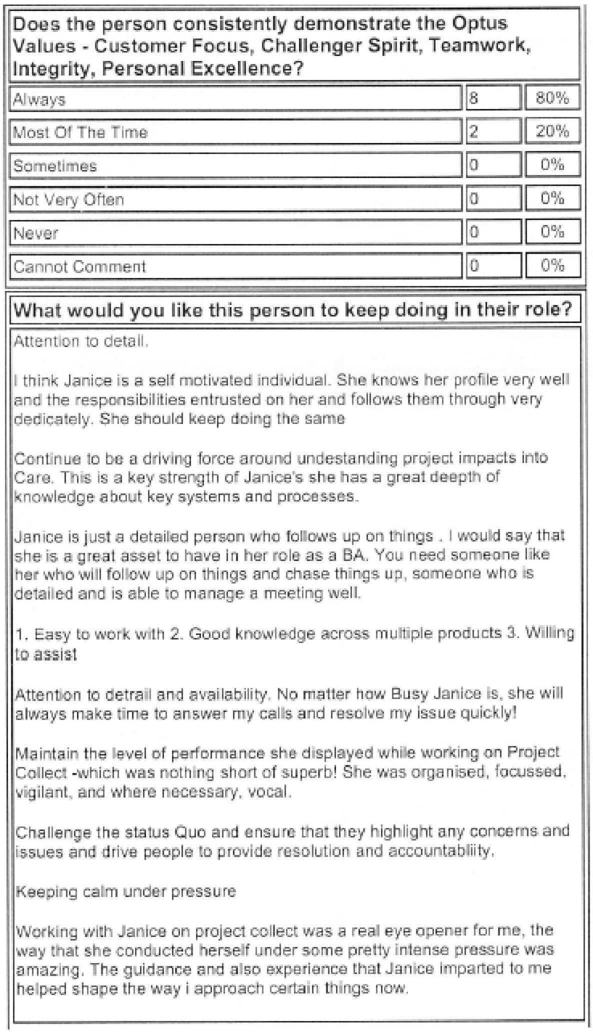
Always	8	80%
Most Of The Time	2	20%
Sometimes	0	0%
Not Very Often	0	0%
Never	0	0%
Cannot Comment	0	0%

Does the person produce work that is of a high standard?

Always	9	90%
Most Of The Time	1	10%
Sometimes	0	0%
Not Very Often	0	0%
Poor	0	0%
Cannot Score	0	0%

Does the person adopt MEWE behaviours and drive a collaborative approach to achieve collective goals?

Always	9	90%
Most Of The Time	0	0%
Sometimes	1	10%
Not Very Often	0	0%
Never	0	0%
Cannot Comment	0	0%



Does the person consistently demonstrate the Optus Values - Customer Focus, Challenger Spirit, Teamwork, Integrity, Personal Excellence?

Always	8	80%
Most Of The Time	2	20%
Sometimes	0	0%
Not Very Often	0	0%
Never	0	0%
Cannot Comment	0	0%

What would you like this person to keep doing in their role?

Attention to detail.

I think Janice is a self motivated individual. She knows her profile very well and the responsibilities entrusted on her and follows them through very dedicately. She should keep doing the same

Continue to be a driving force around undestanding project impacts into Care. This is a key strength of Janice's she has a great deepth of knowledge about key systems and processes.

Janice is just a detailed person who follows up on things . I would say that she is a great asset to have in her role as a BA. You need someone like her who will follow up on things and chase things up, someone who is detailed and is able to manage a meeting well.

1. Easy to work with 2. Good knowledge across multiple products 3. Willing to assist

Attention to detrail and availability. No matter how Busy Janice is, she will always make time to answer my calls and resolve my issue quickly!

Maintain the level of performance she displayed while working on Project Collect -which was nothing short of superb! She was organised, focussed, vigilant, and where necessary, vocal.

Challenge the status Quo and ensure that they highlight any concerns and issues and drive people to provide resolution and accountabliity.

Keeping calm under pressure

Working with Janice on project collect was a real eye opener for me, the way that she conducted herself under some pretty intense pressure was amazing. The guidance and also experience that Janice imparted to me helped shape the way i approach certain things now.

The decade to diagnosis

As earlier mentioned, I first became sick in early 2002, in what had been the best time of my life. At age 27, I was enjoying an active social life, had a fulfilling job, and had recently started seeing Ryan, the man who would eventually become my husband.

I can't pinpoint exactly when my symptoms started; sometimes I think there was a gradual onset, but I also remember that some symptoms seemed to be flicked on like a light switch. I don't remember any specific incident, like a bite, that set me off, though.

I had brain fog (inability to concentrate, difficulty in making decisions, memory loss, problems reading social situations), and was permanently exhausted, even after up to 18 hours sleep per day.

I started experiencing permanent abdominal pain, although mercifully the severity varied. My gut became distended as though I was suffering malnutrition, I had cramping so strong sweat would run down my face from the agony of it. My abdominal area was so sensitive that if my hand touched it in my sleep, I would wake up from the discomfort. I took to padding my stomach with jumpers or pillows before carefully putting my seat belt on in the car.

I vomited at least once a daily – sometimes projectile vomit. I've always been susceptible to car sickness, but this became worse; I often vomited when I was the driver! I also battled through alternating diarrhoea and constipation. I had no control over these (or indeed any) symptoms, so sometimes they occurred in public. I took to carrying around plastic bags in my handbag and car, 'just in case', and had to use them frequently.

The loss of dignity and – to an extent – independence was very distressing, but what was even worse was the fact that I couldn't seem to 'access' my personality. I didn't feel like it had changed, just that it had been overridden by some kind of symptoms that caused me to be irritable, short tempered, less sensitive and less socially aware.

This felt very different from the depression I had experienced in the past; I pictured inflamed nerves in my brain as the cause. The loss of myself was very difficult – probably the hardest thing I've ever gone through.

I had experienced quite a few traumatic events by the time I had fallen sick, but was proud of my ability to get through them; I knew myself well, and I knew what worked well for me in terms of coping mechanisms. I used to refer to this as 'having the map' to get through tough experiences without getting 'lost'. At this time, when I needed the map more than ever before, it was gone.

Each day I dealt with these symptoms, in addition to the new symptoms that occasionally appeared, such as a continual runny nose and phlegmy throat, hot flushes, thrush, a sensation as though battery acid was running through my veins, my stomach 'growling' so loudly at night it would wake me up, very uncomfortable feelings of hatred and rage directed at absolutely nothing, and a weird, almost electric 'uneasy/impending doom' energy that was physical, emotional and mental. I have since noted with interest that this feeling of 'impending doom' feeling is also reported in patients stung by certain box jellyfish;[1] it's certainly not something purely of psychiatric origins.

Additionally, I had large black circles under my eyes – I think I physically aged about 5 years within a month.

After a few weeks of sick leave, I realised that I had to return to work – rest didn't seem to be helping, my GP didn't have any answers for me, and I had bills to pay.

I tried to exercise, in the hope that this would boost my immune system, but, strangely, this exacerbated my symptoms.

The next 18 months passed in a haze of pain, humiliation and distress. I wished I could be 'put down', like an injured animal; it seemed like the humane thing to do. I did my absolute best to keep suicidal thoughts at bay; as my brother committed suicide as a teenager, I knew the pain that my death would cause. At night, I would lie awake bargaining with God – I was happy to have one of my limbs amputated if only He would take away this sickness, for example.

I had previously been well-liked at work, and had won numerous awards for my leadership and ability to solve customer issues – now, I heard staff bitching about my mood swings and I knew myself that I wasn't making the best judgement calls at times.

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[1] Marine Medic, *Irukandji (Carukia barnesi),* http://www.marine-medic.com.au/pages/medical/irukandji.asp

I was also perceived as being ‘too intense’ – and I was! But I had to work myself up each day to that level of stress/intensity to form a degree of the concentration and physical energy needed to get through anything resembling normal life.

Everything I did took a huge amount of effort; simply walking around, I felt like there was some kind of resistance, like I was walking through water. At my sickest, I used to think that grocery shopping took a couple of hours; surely it had to, based on how exhausted I felt afterwards! To this day, I think of that feeling every time I go to a supermarket, although I now realise my shopping takes just 45 minutes.

The smallest things seemed like huge challenges – I remember bawling my eyes out whilst trying to scrub some dried vegetable off a colander, due to the physical effort involved.

Some of my friends started dropping out of my life, and I encouraged others to do the same. I didn’t see any point in explaining to them how I felt; even to my own ears, it sounded dodgy, like I was blowing things out of proportion.

I began having what I assume were spatial awareness issues – I was constantly accidentally cutting myself with knives and bruising myself on the sides of tables. It wasn’t long before every plate I owned was chipped from being clumsily handled while washed.

I also regularly bit my tongue and lips while eating.

I suggested to Ryan that we should break up. He is 6 years younger than me, and the pressure (applied by me, not Ryan) to be a worthwhile companion to a guy in his early 20s, when I felt about 100 years old myself, was hard to live with, day-to-day. I knew that if I could ‘leave’ myself I would, so it was only fair that he should be given the option to leave me, without feeling guilty. I encouraged him to go and find a girlfriend who didn’t spend most of her weekends sleeping, and the rest either on the toilet or sitting around with an angry black cloud over her head. He refused – I was both relieved and disappointed.

During this time, of course, I did everything I could think of to find answers when I had the energy – I saw GPs, gastroenterologists, naturopaths, a Chinese medicine practitioner and an iridologist. I had ultrasounds, comprehensive blood tests, stool tests, colonoscopies, an endoscopy, a helicobacter breath test, colonic irrigation, and something called ‘natural energy therapy’. I drank potions, mixed powders, swallowed anti-nausea medication, inhaled essential oil-laden air and had a weird zapper contraption applied to my spine.

Nothing helped, and the only result that indicated anything might be wrong was a blood test identifying a minor elevation in my white cell count, indicating an infection was present.

Some doctors were honest and supportive (“*I really don’t know what’s causing the problem, or who can help, but if you come up with any ideas, please let me know and I’ll do my best to support you*”) and others were downright ignorant, disrespectful and rude (“*It’s just Irritable Bowel Syndrome – deal with it, some people have cancer”, “It’s all in your head – yes, I can see you are very bloated, but <u>all women have fat days</u>*!”)

Some were defensive. “*What do you want me to do about it??!!”* a GP yelled at me when I dragged myself into his surgery to report no improvement in my symptoms. “*Why are you here? You’ve already seen [name of gastroenterologist redacted]; he’s a good friend of mine and an extremely good doctor*” my second gastroenterologist said, before eventually relenting “*OK, well I’ve inserted my finger into your anus, and there’s nothing there, but if you want to waste your money on a colonoscopy, I’m happy to take it!”*

Ryan and I continued on living life the best we could. I was way too exhausted to use the $5000 travel voucher for anything exciting, so it was spent on a bus trip around New Zealand's South Island with a bunch of people at least 40 years our senior. I spent most of the time sleeping, and Ryan spent most of the time staring out the window at sheep and getting hassled by the retirees about whether he could liven up the trip by proposing to me (he didn't – I had told him I wouldn't accept a proposal while he was under 25; he was simply too young to be making a commitment to me and my situation.)

Facing indefinite illness, I worried about my financial future; particularly my ability to pay medical bills as I continued the search for a cure. As the housing market was booming, we made the decision to spend my life savings on a deposit for a house in a low income area on the [name of location redacted]. We finally found a dilapidated house with holes punched in the walls, water damage and a history of previous druggie tenants (according to our neighbours). It was 2 hours away from family, friends and our workplace, but I felt relatively comfortable that if I had to stop working fulltime, we'd still be able to afford the mortgage, unlike rent in Sydney.

Help eventually came from a most unlikely source. In October 2003, I was seriously assaulted in the "*bag snatch gone wrong*".

I spent a few days in hospital on a drip, as I was too nauseous to eat. Somewhere in my even-foggier-than-usual-brain (I had a head injury), I realised that my gastrointestinal symptoms were easing for the first time.

Due to the severity of my head injury, it wasn't until early 2005 that I fully realised the implications of this – maybe food was playing a factor in my illness?

After a few false starts with dieticians, I found my way to the [name of a hospital allergy clinic redacted], where it was confirmed that I had severe food intolerances.

I began following the strictest version of their Elimination Diet, which consisted of foods with low salicylates, amines and glutamates, and from there, was able to identify further foods causing problems. I ended up limited to only seven foods, but it was worth it - in a matter of months, my GI symptom severity reduced by about 75%. I soon noticed that the random feelings of anger and hatred more often than not occurred within an hour of eating foods I had an intolerance to, unless I'd been consistently eating only the seven allowed foods for at least a month (presumably when I am very strict on my diet it takes longer to reach that intolerance threshold).

Life was now more manageable, and to my relief, my personality started to come back, completely unscathed! Part of me often listened with amazement as I found myself confidently chatting away with complete strangers without a care in the world. Weirdly enough, although I was working in a completely different department at the time, a new colleague gave me the nickname 'Budgie' for the same reasons as the first colleague.

However, the diet was very restrictive, left huge gaps in my nutrition, and was not conducive to a normal life. While I was feeling much better compared to what I had in previous years, I knew I was still a long way from leading a normal life with a healthy body.

So the search continued for answers. On a friend's recommendation, I sought help from [name of gastroenterology centre redacted.] Here, a more thorough colonoscopy was performed with a high powered microscope, which identified small red dots throughout. I was diagnosed with an infection – the causal bacteria was unknown.

[redacted]

Whilst I had some promising improvements with the resulting antibiotics, they couldn't be retained long term. As a result, I was offered the 'last ditch' treatment of Faecal Microbiota Transplantation (FMT), which basically means I had the poo of anonymous male donors inserted into my colon via enema. Yep, I was THAT desperate!

The theory is that although science could not yet identify the bacteria causing the problem, preventing effective antibiotic treatment, a good mix of bacteria from a healthy body may be able to eradicate the 'bad' bacteria. This method has been used very successfully for many years on livestock.

I signed up for a two week course of treatment, and asked if this could be carried out first thing in the morning, in the hope that I could head off to work afterwards. I was told that this was what most patients did – some felt a bit sicker, but they were well enough to continue life as normal.

Given how much illness I'd battled through while working for so many years, I was very confident I'd be able to manage it.

I was wrong – early into treatment I became extremely fatigued and lethargic, experiencing pain in my back and joints. I felt like I'd been hit by a truck. This improved after the first few days, and although the staff said it wasn't an expected reaction, a feasible explanation was that it was the result of a 'battle royale' being waged in my digestive system between the new bacteria, and the established source of infection.

As with the antibiotics, I had some improvements in the short term, including increased alertness, regular bowel movements and greater energy - a colleague even passed me a note during a meeting, apologising if I had noticed her staring at me, but that she couldn’t believe how “pink and healthy” my face looked. But again, these improvements couldn’t be maintained long term.

That said, FMT was the only medical procedure to make any difference, so I continued to undergo a week of treatment every 6 months in 2010 and 2011, racking up thousands of dollars in costs.

By this stage, after almost decade of illness, I estimated I’d spent about $80 000 on the search for diagnosis and a cure.

Ryan and I watched our siblings and friends start families of their own, but we were reluctant to do so ourselves – I was worried that my dietary limitations would mean I was unable to provide enough sustenance for the foetus, and that I’d pass on my illness to the baby. I was also cautious about the possibility that the mental illness my brother had experienced could be genetic, and the ‘unease/impending doom’ feeling also reinforced my belief that it would be irresponsible of me to bring a child into our world.

Ryan was also worried about the impact the demands of a baby (healthy or not!) would have on my body.

One particular incident will always stick in my mind from this time – I’d just undergone my poo enema, and had been left by the nurse to perform the second part of the treatment, which is firmly rubbing the abdomen in an anti-clockwise direction for 35 minutes to push the poo as high as possible to coat the colon. Despite having carried out this process many times before, on this occasion there seemed something strangely familiar about it.

Then it occurred to me – it was a very similar movement to that of expectant mothers soothing their babies. At that time, both of my sisters were pregnant, and could well both be using the same motion at that exact moment, to express affection for their baby while dreaming of the future. Meanwhile I was massaging stranger’s faeces into my body for very little reward. At that moment I hated myself and my life so much it literally took my breath away. I never again went into the treatment room without a book and an iPod, to distract myself.

In November 2011, I had to fly to Fiji to be bridesmaid at my sister-in-law’s wedding. I was a bit worried about my ability to stick to my diet overseas, and the possibility of picking up more bad bacteria, and, on my return to Australia, it seemed these fears were justified.

My level of brain fog, fatigue and nausea increased, and I experienced new symptoms: deterioration of my eye sight, dizziness, an insatiable appetite (I’d eat a 300gm steak and 1.5 kg of roast potatoes for dinner, only to wake up in the middle of the night hungry!), my heart racing, my periods lasting for 2 weeks, and occasionally, the inability to swallow, like I’d just somehow forgotten how to do it. I also had intermittent issues with bladder and bowel continence.

Prior to my illness, my normal weight ranged from 48-51kg. About two years into my illness, my weight had stabilised at 45kg, and although I hadn’t lost any further weight since, there was suddenly *something* about my body that made me look far more gaunt.

By December, my GP was becoming alarmed. He started ordering more tests, and I was diagnosed with a thyroid condition called multi-nodular goitre, and also osteopaenia (the pre-cursor to osteoporosis), which was a result of my dietary limitations.

He tested me for some auto-immune conditions, and despite his alarm, couldn't understand why I sobbed my heart out when they all came back negative – I just wanted answers.

In early 2012, I floated between my GP and the [name of gastroenterology centre redacted] – this time, a series of FMT treatments resulted in no improvement at all.

I was still commuting a four hour round trip to work most days, although my excellent boss had allowed me to telecommute a few days a week. Whilst the commute and my work had always been exhausting, now it had reached another level I didn't think possible. I regularly found myself trembling with fatigue on the train home.

My desk at work had partitions just below eye level separating me from colleagues. One colleague was able to accurately gauge how badly I was feeling each morning by simply looking at my eyes, which appeared very heavy and sad, and also quite dead.

I knew that this was it; after pushing myself to the absolute limit for over a decade, my body couldn't cope anymore, no matter how I willed it. I started looking into reducing my working hours, or even resigning, with a heavy heart, as it would bring to an end my campaign to save a lot of money in the hope of diagnosis and treatment.

It was around this time that my sister told me that her step-daughter had similar gastrointestinal issues, and had recently been diagnosed with Lyme disease.

When she suggested I get tested, I felt a bit sceptical – I'd watched media reports on Lyme sufferers with much empathy, but I couldn't relate to their seizures, which seemed to be the defining symptom of Lyme.

I was even more sceptical when I discovered the initial appointment with a GP who had undertaken study regarding Lyme – also known as a 'Lyme literate' medical doctor (LLMD) - would cost around $2000, and involve a 6 hour round car trip, as very few doctors were willing to acknowledge Lyme, let alone treat it. Sadly, even today I don't feel comfortable identifying this doctor, as LLMDs seem to be ridiculed and bullied by others in the medical profession.

However, Ryan pushed me to leave no stone unturned (God love him!), and so the appointment was made.

We soon discovered the reason for the doctor's fee – he spent 90 minutes educating us on Lyme disease, and walking us through a list of approximately 80 symptoms, of which I had about 60%. He also explained that despite the media's portrayal of Lyme, not all patients have seizures; Lyme is a systemic disease and impacts different bodies in different ways, with varying levels of severity – hence the complexity!

The doctor explained that the Australian government don't believe Lyme can be acquired here; as a result, medical staff do not receive training in the disease, and when tests *are* conducted, the processes used are not of a world-class standard.

The doctor, who works in a tick endemic region, therefore had to go overseas to undergo his training via the International Lyme and Associated Diseases Society (ILADS), which assists doctors like him in many countries. He would be sending some of my blood samples to specialist laboratory [lab name redacted] in America for analysis.

Suddenly all the pieces were falling into place – the doctor confirmed that many sufferers have severe food intolerances, and that Vancomycin, one of the antibiotics supplied to me by [name of gastroenterology centre redacted], was quite effective against one form of the three forms of Borrelia (the Lyme bacteria); hence my short term improvement whilst under [name of gastroenterology centre redacted.]'s treatment.

He explained that Borrelia don't survive in oxygenated environments but thrive when oxygen is low – I wondered if this is possibly the reason why my condition deteriorated after my Fiji trip; I would have spent a total of 10 hours in a plane.

This would also explain why I felt worse after exercising, as exercise increases oxygen flow into the blood, causing the Borrelia to die, releasing toxins as it does so (known as a Herxheimer or 'herx' reaction).

The 'hit by a truck' feeling I got shortly after commencing FMT treatment might also have been a herx reaction as the healthy transplanted bacteria attacking the Borrelia.

The doctor confirmed that Lyme can indeed cause mental/emotional symptoms due to inflammation/irritation in the brain. Additionally, the connection between the gut and brain is so influential that the gut is often referred to in medical circles as 'the second brain'.

The doctor told me that based on our discussion, he was "almost certain" I had Lyme, and that it was "highly likely" I had the co-infection Bartonella and "possibly" Babesiosis.

He also told me about the natural killer cell CD57, which is sometimes used as an indicator of the severity of chronic illness. The normal range of CD57 is 60-360 cells per microlitre of blood. People with Lyme tend to have a CD57 count of below 60, and he estimated I'd be "*lower than 60, but higher than 20*."

The doctor was comfortable with the CD57 testing, and other tests including Chlamydophila, Mycoplasma pneumonia, Brucella and Rickettsia being conducted locally.

I desperately hoped that I'd finally found a diagnosis, but after years of empty promises from medical practitioners, I still had my doubts.

I conducted some research on [American lab name redacted], and they certainly seemed legitimate. They were very forthright in stating that although their testing had played a part in the diagnosis and subsequent successful treatment of patients, it wasn't yet perfect, so doctors should use the tests only as part of a diagnosis decision, primarily relying on clinical diagnosis (ie the doctor's observations, and discussions with the patient).

I believe this shows a lot of integrity on [American lab name redacted]'s part; they certainly aren't the snakeoil salesmen that Lyme deniers have made them out to be. Their message is also consistent with the American Centres for Disease Control and Prevention, who state that "*Lyme disease is diagnosed based on:, Signs and symptoms, A history of possible exposure to infected blacklegged ticks. Laboratory blood tests are helpful if used correctly and performed with validated methods.*"[2]

When the test results arrived, it was clear that my doctor was on the right track. My IgM Western Blot result was positive for Borrelia. My Bartonella henselae IgG was equivocal, which my doctor explained to me he considered to be a 'positive' result, as in addition to my Bartonella-specific symptoms, it is notoriously difficult for patients to receive anything other than a negative result in Bartonella tests.

My Babesiosis test was negative, but again, based on my symptoms, my doctor decided to keep an open mind about that, and monitor the symptoms most likely to be caused by Babesiosis, during treatment.

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[2] Centres for Disease Control and Prevention, *Lyme disease – Diagnosis and Testing*, https://www.cdc.gov/lyme/diagnosistesting/index.html

It is worth noting that each page of the test results comes with a message that "*Diagnosis should not be based on laboratory tests alone. Results should be interpreted in conjunction with clinical symptoms and patient history.*" Again, I believe this shows integrity on [American lab name redacted]'s part; they do not mislead patients with false claims.

[redacted]

[redacted]

[redacted]

My CD57 count, assessed by the Australian pathology, was 30.

[redacted]

My reaction to my diagnosis was dizzying relief at finally having an answer; having a name for the condition that was so mercilessly hounding me, anticipating that people would respond to that name and not continue to expect me to act like a healthy human, nor be nasty or dismissive of me when I couldn't live up to that standard.

I also felt validated – here was proof I wasn't lying; it wasn't "all in my head", I wasn't an attention seeker, and I wasn't the awful person that in my most vulnerable moments my moods led me to believe I was.

My doctor warned me that treatment would take one to two years, be quite aggressive, and that at some point I would need to stop working in order to cope with the herxes. Given that some of the antibiotics required to treat the different forms of the Borrelia (Azithromycin and Clindamycin, as well as Wellvone if I was found to have Babesiosis) cost hundreds of dollars a month, I decided to continue working for the time being.

I reasoned I had already willed my way through so much, there was no way I couldn't cope with at least the initial stages of treatment.

Full list of my symptoms

Neurological	
Brain fog - memory loss, difficulty in concentration and comprehension, spelling difficulties, word block, confusion	Hypoperfusion to bilateral temporal and posterior parietal lobes
Mood swings	Suicidal ideation
Reduced spatial awareness	Headaches
Frequent accidental biting of tongue and lips	Reduced coordination
Sense of impending doom	Baseless feeling of rage
Sensitivity to touch	Temperature dysregulation
Noise sensitivity	Light sensitivity
Difficulty swallowing	Temporary facial paralysis
Slurred speech	Repetitive quality to speech
Robotic sounding speech patterns	Tremors
Involuntary twitches	Presence of 'flashing lights' when closing eyes
Mental hyperstimulation	
Gastrointestinal	
Severe abdominal cramping	Chronic vomiting
Alternating diarrhoea and constipation	Bladder and bowel urgency
Bladder and bowel incontinence	Gut distention
Blood in stool	Pruritis ani
Increased motion sickness (when driving self, scrolling too quickly on a webpage)	Nausea
Hypochlorhydria	
General	
Severe fatigue	Weight loss ("very underweight" on BMI scale)
Extensive food intolerances	Menorrhagia
Frequent bruising	Pain behind eyes
Reduced vision (Note: may be coincidental timing)	Pain in ears
Tinnitus	Tachycardia
Salivary hypofunction	Xerostomia
Severe menstrual pain	Tingling feet
Teeth chattering	Low blood pressure
Severe cystic acne	Inability to walk due to fatigue and/or dizziness
Breast pain	Decreased sex drive
Insomnia	Fevers
‘Cold patches' on body	Crawling' sensation that travels across body
Muscle cramps	Air hunger
Dizziness	Dental pain
Genital pain	Early morning waking
Drawn/grey complexion	Puffy 'dead' eyes

No appetite	Voracious appetite
Pins and needles feeling	Scratchy' sounding voice, as though of a sore throat
Night sweats	Low thyroid function

Diagnoses

During my 14 year illness, I have been diagnosed with the following (in roughly chronological order):

Irritable Bowel Syndrome
Osteopaenia
Multi-nodular goitre
Lyme disease
Bartonella
Babesiosis
Chronic Fatigue Syndrome
Postural Orthostatic Tachycardia Syndrome
Chronic Inflammatory Response Syndrome (tentative)

My treatment

Antibiotic treatment for Lyme as recommended by the ILADS guidelines[3] involves a minimum of three antibiotics; one for each form of Borrelia (spirochete, cyst and cell wall deficient), and potentially extras to deal with the co-infections, although sometimes the Lyme antibiotics can also treat these.

Despite the fact that so many of my symptoms were related to the gut, I began oral treatment in July 2012, as it can be difficult to obtain a peripherally inserted central catheter ('PICC line') for such a controversial disease – given the negative attention they receive, most LLMDs will either not even request a PICC, or will do so only in the very worst cases, in which neurological damage is severe enough to cause seizures.

I had to simply hope any irritation the antibiotics caused to my gut would be outweighed by the benefits of treatment, and started the recommended probiotic and herbal regime to support my system.

As with my FMT treatment, I was too optimistic about what I could handle. My doctor had told me to expect a herx within 5-6 days of commencing treatment of Plaquenil, and it did come within that timeframe, and it came hard. I was very dizzy and literally had to scoot around the house on my backside instead of walking. I also had difficulty speaking; it was like the message of what words I wanted to use took much longer than usual to reach my mouth.

As anticipated, it was over within 12 hours, and I was back to baseline again for another week or so, then the cycle repeated itself. My doctor was very careful to minimise the impact this had; he suggested I take the capsules at night to minimise the impact on my life, and would not introduce another antibiotic until the Plaquenil herxes had eased in intensity.

He also requested monthly blood tests to assess whether my liver was functioning despite the high dose antibiotics, among other things.

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[3] Burrascano, *Advanced Topics in Lyme Disease,* http://www.lymenet.org/BurrGuide200810.pdf

During this time, his receptionist regularly scheduled 15 min phone appointments at no cost, so he could monitor my condition.

I was also advised to visit an ophthalmologist, given Plaquenil can cause eye problems. The specialist I chose sympathised with my condition, explaining he had grown up on the Sydney's Northern Beaches, a notoriously tick endemic area, and had no doubt through his observations there that Lyme could be – and was – locally acquired.

As the weeks went by, it became obvious the treatment was taking a toll on me, and my manager made arrangements for me to work on smaller, less stressful projects, and work from home more often. While I continued to perform well, it was obvious that the possibility of ceasing work as my LLMD had mentioned, would soon become a reality.

Due to my consistently strong performance, my manager was able to convince the Human Resources department that I should be allowed 6-12 months unpaid leave, in preference to me resigning and the company losing a good employee.

My manager also took the time to discover that the company's superannuation provider [name of superannuation provider redacted], had included income protection insurance in the standard package. That was so very much appreciated, as Ryan and I were so caught up in the whirlwind of learning about Lyme, its treatment, and engaging with the Australian Lyme community, that we hadn't even had time to consider money.

I finished working on 5 October 2012, to focus on treatment full time.

Around this time, I discovered through the Lyme community that there were doctors in Sydney who treated the condition, so I transferred to one of them for convenience, and also started Skyping with a naturopathic doctor in America, who has significant experience in treating Lyme (and has even written a book, 'Lyme disease in Australia') for assistance with herbal remedies.

At my practitioners' encouragement, I spent a lot of times researching Lyme treatment, and also other possible illnesses that may play a part in my illness. The impression I get is that Lyme deniers think patients blindly follow their doctors' advice; that was not the case at all for me – my (educated) input was encouraged; the treatment plan was a team effort. I know many other patients who had the same approach. Carers also had a similar approach when their loved ones weren't well enough to undertake their own research.

Janice Foster
November 9, 2012

Hi Tigers! I've been getting messages from some of you hoping I'm enjoying "lots of rest", so I thought it was time for another 'sneak peek' into Lymie life.

So far, no rest. Because the Aussie medical community know so little about Lyme, its up to Lymies to research many of the different treatment options themselves.

Here are some of the books I've been referencing. So far, 2.5 highlighter pens have sacrificed their lives on these pages. See, Lyme sucks for everyone!

[redacted]

[redacted] are you chillaxed yet?
November 9, 2012 at 1:54pm

Janice Foster Erm...NO! But I think within the next week I'll be comfortable that I have a 'basic' knowledge, even though my brain's not retaining much.

Geez, I long for the days of 800 line DBRS' (OK, not really, but almost!)

Despite antibiotic and herbal treatment, regular use of a far infrared sauna and a rife machine, lymphatic drainage massages, removal of amalgam fillings and probably many other things I can't remember, I had no significant improvement in my health by the end of 2012.

My new LLMD and naturopathic doctor agreed with the original LLMD about the possibility of a Babesiosis infection, so I tried an antibiotic challenge, that gave me my worst herxes yet. Accordingly, I started antibiotic and herbal treatment for Babesiosis, and, like with Borrelia, the herxes were clearly defined and consistent, but didn't seem to result in any improvement.

By February 2013, eight months into my treatment, my doctor began to seriously consider use of a PICC line, but wasn't comfortable arranging it herself for fear of being targeted by the Australian Health Practitioner Regulation Agency (AHPRA), at the expense of her career and her other patients.

It appeared the only 'correct' way to obtain a PICC, according to the medical community, was via an Infectious Diseases Specialist (IDS). I made an appointment with [name redacted] at [location redacted] Public Hospital, who I understand is now [job title redacted, but essentially it's a significant promotion].

On the day of my appointment, my brain was particularly fogged, and I was showing a relatively recent symptom of speaking very repetitively; it was like I was a broken record getting stuck on a word or two per sentence.

Despite the reputation of IDS' as being very dismissive of Lyme patients as 'fakers', I found [name redacted] to be very kind, thorough and open to the possibility of a Lyme diagnosis (although I am aware other patients have reported otherwise). He was very quick to acknowledge "There's definitely something wrong here", but refused to accept the [name of American lab redacted] results.

He said that if I could get a positive Lyme result from "any lab in Australia", he would arrange for a PICC to be inserted, for administration of the antibiotic Flagyl, for a period of one month, which he believed was all that was necessary.

I knew that the more scientifically minded members of the Lyme community had concerns with the standard Australian testing processes for Lyme, for reasons they were clearly able to explain, citing appropriate references. Some of that information is now available on the Lyme Disease Association of Australia (LDAA) website.[4]

I became aware that a local lab called [name redacted] was working on some alternative Lyme tests, but that they were also having trouble obtaining accreditation from the National Association of Testing Authorities (NATA), so I called [name of IDS redacted]'s receptionist to ask if he'd accept test results from them. The response relayed to me was "*Any* Australian lab." The fact that [IDS name redacted] didn't insist on NATA accreditation will become more significant later in my story.

During our appointment, [IDS name redacted] repeatedly asked me "*Are you sure you don't remember a tick bite?"* and "*Are you sure you'd never been overseas before you became ill?*" Once he followed up the second question by saying something like "*Not even to Canada?"*

At the time I didn't pay that any attention, as my brain was too busy scrambling to keep up with the conversation, but afterwards, Ryan and I talked it over, and it really did seem that he was asking leading questions to convey that I should change my story so he could help me.

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[4] Lyme Disease Association of Australia, *Why is Lyme disease controversial?* http://www.lymedisease.org.au/part-2-lyme-politics/#onlyaustesting

At one point he also mentioned something along the lines that the Lyme controversy "*really requires doctors to dot there I's and cross their t's*", but I can't remember if that was in relation to diagnosis or length of treatment.

I've never publicly shared this full anecdote before, and seriously considered not doing so now, for fear of landing [IDS name redacted] in hot water, but after so many years of activism failing to progress the cause of Lyme patients significantly, I feel like it's time for 'gloves off' – I might not ever get another opportunity to share this information. So I'm 'outing' [IDS name redacted] in the hope that he will share his experiences as an IDS under pressure. (Thank you for your compassion and initial help, [IDS name redacted], and apologies for putting you in this position.)

By the way, if my interpretation is correct, and [IDS name redacted] does believe that Lyme can be locally acquired, then he's not the only IDS to feel that way. During the 2014 Karl Mc Manus Foundation's (KMF) Tick Borne Disease conference, an attending IDS stood before the audience during discussion time, declaring that he diagnosed his colleagues with "Borrelia Blindness".

After discovering that [local lab name redacted] testing required me to cease all antibacterial treatment for over a month first, and with the knowledge that one month of Flagyl was unlikely to be particularly helpful (given both the short treatment period involved and the fact that Flagyl doesn't address all forms of Borrelia), I decided against pursuing a PICC, and instead introduced Bicillin, an antibiotic that is administered via intra-muscular injection.

My LLMD started me on half an injection once a week, slowly working up to two injections every three days. This was initially performed by my local GP, but when he moved surgeries, the drive to his new location was much longer, and also on a road with more roundabouts, which resulted in me vomiting on several occasions.

My LLMD then requested the injections be administered by the local community nurses. Given they are government employees, I was unsure of how they would react to a Lyme diagnosis, but soon discovered they knew nothing about the condition. Several of the nurses read up on Lyme after treating me, and one told me he'd even printed out information for the rest of his team to read.

I think part of the reason the nurses were so accepting is that Bicillin injections are apparently huge. A few of the nurses told me they didn't want to inject me for fear of hurting me, and another flat out refused to do it, only relenting when I threatened to inject myself, as some other patients do. I guess they assumed that no one would go through that treatment unless they had to!

Over the next couple of months, I lost a few more kilograms, and my hair started to fall out in clumps. I also became weaker and had to be put on Zofran, an anti-nausea medication costing $8 a pop, usually used by chemotherapy patients. (In fact, I've often heard Lyme treatment compared to chemo; one patient in an American online forum said she'd previously had breast cancer, and treatment was "a piece of cake" compared to Lyme treatment, but I think that was partly in context to the support of the medical and general communities that cancer patients receive).

Below is a photo I took on 14 April 2013 of a clump of hair that came out while I was shampooing:

My LLMD monitored my monthly blood tests diligently, but things never got dire. This seemed to be my ‘rock bottom’ period, because shortly afterwards, I began to put on weight again, and finally feel quite a small, though consistent, improvement.

Below left is a photo of me taken in February 2013 for a Lyme awareness video (the small photo to the left of me is from my pre-illness days; as you can see, my face is much rounder and my body shape more curvy). I have doctored the sign to the right of me to reflect the date, as it had writing on it relating to the video, that doesn’t make sense outside that context.

As you can see, the photo taken in July shows a marked improvement.

Ryan and I could see an end in sight, and tentatively but excitedly began to discuss the possibility of me returning to work, and what that might involve.

By late August, however, things were getting a bit wobbly again, potentially due to stress (see [patient’s name redacted]’s story in the ‘Patient Stories’ chapter). However, my weight continued to improve, and in September, I was back over 50kg for the first time in about a decade:

Janice Foster
September 5, 2013

Woohoo - now over 50kg on everyone's scales! Suck on THAT, bugz!

[redacted] and 56 others

View 15 more comments

Janice Foster Natalie, bring it on, girlfriend! I've put on 7kg this year, though, so watch out, I'm on a roll!

I don't really think there is anything we can do to control whether we put on weight or not - my eating habits and appetite hasn't changed. I think the o... See More

September 6, 2013 at 12:54pm · Like · 1

[redacted] 10
I think
7kg oh god I have no hope!!!... See More

September 6, 2013 at 12:56pm · Like

Janice Foster Yeah, sorry, I guess I've got a head start on you, coz I'm not as sick. But when you do put on that weight, it's going to be all the more impressive!

September 6, 2013 at 1:10pm · Like · 2

Overall, however, improvements were still not as significant as expected, and by October, my LLMD was urging serious action. Although 'flashes' of health were encouraging, by now she expected my health to be much more stable. Despite knowing that she had some patients enjoy great success at the Lyme/cancer clinics in Germany, I had a very strong gut feeling it wouldn't work for me – so strong that when I was discussing it with a fellow patient, I got goosebumps.

Hyperbaric oxygen therapy was also discussed, but there were no practitioners in NSW that offered the prescribed levels.

The only viable option seemed to be revisiting PICC treatment. During 2013, increased media attention and the launch of the first KMF Tick Borne Diseases Conference resulted in greater awareness of Lyme, and an influx of GPs willing to help, under the guidance of LLMDs.

My LLMD transferred me to one such doctor, and after several careful hours assessment and discussion in which we referred to medical texts and sought input from the LLMDs, he agreed to consider PICC treatment.

Firstly, however, he wanted Ryan to undergo a 'practical exam', to prove he was able to safely administer the treatment at home without risk of PICC contamination. As a Type 1 Diabetic, Ryan had a thorough understanding of infection control, and passed the test with flying colours.

The PICC was inserted in December 2013, and antibiotic and nutritional supplements commenced. My community nurse was enlisted to change the dressing every week. Things were looking promising!

My new LLMD was extremely diligent in managing the PICC care, and provided me with his personal mobile number and email address should I have any problems over the Christmas period.

It's worth noting here that I did actually have a small problem with the PICC, and I mention this only to illustrate the different attitudes towards patients in different hospitals. I had been standing on a chair hanging up Christmas cards, when I slipped and put my PICCed arm out very quickly to balance myself. This seemed to 'pull' the line, resulting in tachycardia and shortness of breath.

My LLMD had told me to go to hospital if I had any problems at all with the PICC. Although I very much did not want to do, due to the reception other patients have received by hospitals (see 'Patients Stories'), I reluctantly made my way to my local hospital at [location redacted].

The young doctor asked me why I had the PICC, and when I explained it was due to Lyme, to my surprise, he replied rather humbly "I'm not very familiar with that condition. Could you please tell me if the symptoms you are experiencing now are ones you commonly experience?"

I spent several hours at the hospital, waiting for a chest xray to confirm the location of the PICC hadn't changed. During this time, my heart rate and breathing finally returned to normal. While I was waiting to be released, I heard several of the doctors whispering outside the door. My heart filled with the familiar dread that at the very least, someone was going to say something upsetting about Lyme to me, and that at most, my LLMD was going to be reported.

I tried to hear what they were saying, but couldn't make out exactly, however one seemed to be reassuring the others regarding the fact I lived only a few kilometres away, and that I'd said my husband would be home from work soon.

Finally, one of the older doctors shuffled sheepishly back into the room, and said *"You've probably heard us discussing you outside. I just wanted to check – are you sure you are feeling OK?"* When I replied that I was fine, he asked me to look into a mirror, and tell me if I noticed anything unusual. I did not. The doctor moved about restlessly and eventually asked "*Um…is your face always that colour?!"*

It turns out the doctors thought my complexion was very grey, and were worried about sending me home as a result. They had hesitated to ask me about it though, in case it hurt my feelings. How sweet is that?! Fortunately, I could confirm I always look this bad (!), and was then released.

My conclusion from this is that the response of hospital doctors to Lyme patients seems to be dependent on location, and, one can surmise from that, hospital culture. It's a pity more hospitals don't have the culture of [hospital name redacted].

Anyway, slowly more antibiotics were added to my IV regime, until Ryan had a gruelling administration schedule. Depending on the day and the week, he was sometimes up at 4:30am to administer my morning doses, before leaving for work at 5:30am to work a 12 hour shift. He'd return home around 8:30pm, and hook me up for my evening doses.

It was very expensive and time consuming, but we had extremely high hopes for the outcome. We'd known much sicker people than myself who had improved very significantly while using a PICC, and they weren't even people who primarily had gastrointestinal issues, meaning their improvement couldn't be attributed to oral antibiotics no longer irritating their guts.

Unfortunately, it was not to be – for every step forward, there was a half a step backward. Although my herxes slowly and consistently declined in severity, indicating a reduced load of bacteria in system, the anticipated dramatic improvement in my health did not eventuate. By my appointment with the LLMD in June 2014, it became apparent that the PICC, though helpful, could not be relied on as my primary treatment. Although my doctor was willing to persevere with me, there were no more obvious viable options to try – a PICC or the German clinics are the pinnacle of treatment available. In my experience with the Lyme community, I'd never heard of anyone not improving very significantly with a PICC. Ryan and I cried all the way home.

I felt like such a terrible burden in his life; if not for me, he could be in a relatively carefree relationship with a healthy drama-free woman, have his own children, and live in a nice house, close to friends and family.

Instead, he was stuck in a dodgy house in Woop Woop with someone who bought as little to the relationship as a pet (or a Roomba; I usually got the housework done), but took so much more. So much time, energy, emotion and money – hundreds of thousands by this stage, not to mention so much of what should have been the best time of his life. So much beautiful, blissful ignorance.

I really wanted to be dead. Far from being a horrible act, it would have been one of mercy to me, but I knew my family wouldn't see it that way. People often say "I would die for you" to express the depth of their love for someone. That doesn't impress me much; for all we know, there is nothing after death, or maybe a nice fluffy cloud in heaven as a reward. There's not much sacrifice involved in that.

It's much harder to *live* for other people; to know that what you are going through with grimly gritted teeth has no expiry date, to realise that any hope is pretty much without basis, and that life will be just an endless path of enduring things that the people around you have no concept of, and that they will continue to see you purely through the context of their own very different (almost alien to me, by this stage), lives.

But living for others was all I could do; they might not be aware of it, but *I* would know; *I* would know that no matter how little value my life seemed to have, I was contributing just by allowing family and friends to continue on with their lives without dealing with my suicide.

It was an horrific time, and one I often got through often by pretending that I didn't exist. When things were at their worst, I would lock myself alone in a room, and immerse myself in my only release; the sweet escape of a book. I would pretend that nothing existed outside that book – I didn't want Ryan or my dog Schnappsie or any living thing to notice me, or even to think about me, because that would bring me back to reality, and to existence.

At this time I began a retreat from Facebook (my only consistent lifeline to friends, both from the healthy and Lyme communities) that by March 2015 would become complete.

I continued to see my LLMD, and another, more local LLMD who has significant experience in dealing with gastrointestinal issues, food intolerances and environmental issues. They were so gentle with me, these doctors, so compassionate; they could see 'me the person' and 'me the patient' and the gaping divide between. They could see my bewilderment at living in a society where I couldn't even *pay* many of the medical profession to care about me, and my baffled fear at a government who have heard the voices of Lyme patients and ignored them. They were the closest thing I had to understanding other than Ryan (who is truly the gift of my life), and their presence was just pure grace.

I maintained my PICC, so we could use it for the administration of supplements to encourage further healing.

Far from being the Lyme obsessed charlatans that LLMDs are often made out to be, my doctors explained that while it seemed that Lyme had ravaged permanent damage on my body during its decade of freedom, we needed to revisit possibility of other conditions unrelated to infections could be causing roadblocks to recovery.

They methodically cast the net for answers further out, having pathological assessment of my DNA, and also looking for the presence of toxins in my blood via an English lab. Somewhere along the line the presence of mercury was discovered – I haven't included a screenshot of those test results because to be honest they are too technical for me to understand, so I don't know which results are particularly relevant. In the past, I would have spent hours armed with a dictionary, but I'm now just too tired…and my illness has just such an overwhelming presence in my life that the thought of giving it any more 'room' in my brain is repellent.

Anyway, so the local LLMD has been managing a gentle mercury chelation protocol for me ever since, aimed at minimising further damage to my already ravaged body.

We also discussed Chronic Inflammatory Response Syndrome (CIRS), an illness caused when people who have faulty HLA DR genes experience a significant mould exposure, preventing the effective detoxification of the mould from the body.

Some Lyme patients, particularly those who had returned from treatment in Germany but were still struggling with significant residual symptoms, had had a lot of success with treating CIRS.

Having been exposed to mould via a leaking shower at the address I lived at when I first became ill, I thought it was worth investigating. I was in such a bad mental state that it took time to build up the strength to hope again, but with the encouragement of my LLMDs and fellow patients, I finally had my blood assessed at an Australian lab. Sure enough, I had some faulty genes.

I made an appointment with another doctor, in another state, who was treating both Lyme and CIRS patients. Whilst awaiting this appointment, I had my house assessed by a mould specialist who works with [name redacted], the American doctor responsible for much of the medical professions knowledge of CIRS. Whilst there was some mould present (the house was on the low side of the street), the house was not unusually mouldy. The mould specialist thought it this could be easily fixed by wiping the house down with a vinegar solution. Given the weakened state of my immune system though, he also highly recommended the installation of a ducted air purifying system, particularly in case there were any microbes present.

He also suggested I be tested for an infection called Multiple Antibiotic Resistant Coagulase Negative Staphylococci (MARCoNS), which is very common in CIRS patients, as my voice sounded very congested.

Unfortunately, the house had a concrete slab and cathedral ceilings, making the air purification system pretty much impossible to install. On our behalf, the specialist contacted a trusted company who install ducting with a possible workaround, but that company didn’t even both contacting him back, so that ruled that option out. Ryan and I decided if CIRS was an issue, we’d sell our house and move.

This decision was a big one – we’d only recently finally paid off the mortgage on the house, and that had eased some of my distress about the debilitating cost of my ongoing treatment and inability to contribute to household finances.

I finally had my Skype appointment with the CIRS doctor, who prescribed cholestyramine to chelate mould from my body, and requested further blood tests, and a nasal swab for MARCoNS.

Within a startlingly short amount of time after commencing cholestyramine, my weight increased over the 50kg threshold again and stayed there. I tested positive for MARCoNS, and this was also successfully treated.

(It is worth noting here that I was unaware I had any nasal problems until I felt the difference post-treatment. Ryan, too, was unaware that my voice had been very nasal until it was pointed out by the mould specialist.

This is very common in patients and their carers; they become so used to symptoms that they can’t remember what normal is. My regular community nurse [name redacted] commented on this several times – I remember on one occasion in particular, I mentioned feeling dizzy, and asked to sit down for a minute. She took my blood pressure and was alarmed to find it was 62/80, or something along those lines. Given the context, she actually contemplating calling an ambulance, but I just looked at her like she was crazy; as far as I was concerned, this dizziness was just a common blip. And yet there are doctors dismissing chronically ill patients as attention seeking fakers...)

My TGF Beta 1 score, as assessed by an American laboratory was high, which was to be expected in CIRS patients.

[redacted]

However, one of the other markers, Vascoactive Intestinal Peptide (VIP), as assessed by an Australian lab, was high, which is inconsistent with CIRS. This meant it was either possible I didn’t have CIRS (despite the faulty genes, my mould exposure had been less significant than first thought), or that the local lab may be giving an i[redacted]rect result.

[redacted]

My CIRS doctor spent much of the first half of 2015 liaising with Australian labs to try and ensure gold standard testing, in case unexpected patient results such as my VIP score were incorrect.

In the meantime, given my improvement under CIRS treatment, Ryan and I started looking for a new house. It was very difficult to find a nice one without at least some presence of mould (even if not visible), given the low lying, coastal nature of the area.

However, Ryan and I were anxious to make a move, particularly given the huge real estate boom and upward curve in prices, and in late March bought an elevated, well ventilated house, with plenty of access for ducting, just over a kilometre away from our old house.

I felt markedly better upon moving into the new house in late May, and dealt surprisingly well with the constant presence of tradies dealing with mould prevention renovations. By August, Ryan and I were tentatively talking about how I might go about returning to work in the new year.

During this time, the CIRS doctor arranged for his patients with results he wasn’t fully confident of, to have their blood sent together to America for testing.

When the results returned, it was great to see my elevated TGF Beta 1 score had significantly reduced, but my VIP was still high. To date, I still don’t definitively know if I have CIRS.

[redacted]

My CIRS doctor continues to work with his mentor in America regarding the cases of patients including me, and the direction in which treatment should progress.

In November 2015, my health took another dive, taking months to recover. I'm not sure what the reason for this is; possibly my infection is of a relapsing nature. It's probably worth noting that NSW had just experienced its hottest Summer in 150 years, and heat is my kryptonite, particularly when it comes to fatigue, so that may have an impact.

In December 2015, my PICC was removed, after reaching the two year maximum my LLMD felt assured of its structural integrity.

At the moment, my treatment is centred around the ongoing efforts to heal my gut (which now, during good periods, can tolerate 23 different foods, more than three times what it could manage before treatment commenced), stabilise my thyroid and hormones, and chelate mercury. I am also taking a large number of nutritional and herbal supplements, to support my body in ongoing healing and repair.

Additionally, I have been seeing a Functional Neurologist, who prescribes me brain exercises that encourage correction of neurological issues. In tangible terms, these exercises have very quickly returned my absent gag reflex, and my salivary glands to normal functioning after a prior diagnosis at the [redacted name of dental hospital] of "salivary hypofunction".

My weight has been consistently stable at approximately 50kg for over a year.

It's clear from my treatment journey to date that Lyme isn't the only issue my body is battling, or if it is, it's a different strain of Borrelia (or Borrelia-like bacteria) to the American and European strains around which ILADS treatment guidelines are written.

I believe that the stress and trauma of not only the lack of support available to patients, but the ongoing frequent denials of appropriate responses from government and medical authorities (which you'll read about in the coming chapters) have also severely impeded my recovery.

Certainly, I believe it has directly affected my thyroid. After having undergone successful treatment for an extended period, I experienced a resurgence of symptoms shortly after this inquiry kicked off. My doctor suspected that the effort involved in writing my submission, and my distress at the comments made in the media by Drs Brad McKay and Michael Gannon, may have impacted my thyroid. Serology confirmed my thyroid was impacted. Now after several months, my thyroid has returned to normal again.

[redacted]

As earlier mentioned, it's also possible I might have some kind bacterial relapsing fever, of which I believe the KMF are looking into.

Regardless, I think the primary issue is a bacterial infection, based on the below:

- Reporting of herx reaction in relation to FMT, before I even knew what a herx was, thereby negating the possibility of a placebo effect
- I was able to check off approx 60% of Lyme and co-infection symptoms listed on a four page checklist (This may not seem like a high percentage, but apparently it is, for a systemic illness that can effect patients in a multitude of ways)
- Ability to identify with the symptoms and experiences of many other Lyme patients, including those who remember a tick bite
- [Name of American lab redacted] blood test results indicating Borrelia infection, and possible Bartonella infection
- Consistent herx history and improvement relating to antibiotic and microbial treatment
- Significant and sustained increase in symptoms following plane trips, which may be attributed to the low oxygen environment that Borrelia thrives in
- Significant but short term increase in symptoms following periods of exercise, possibly a herx reaction to increased oxygen to the blood stream
- Agreement of clinical diagnosis by four different LLMDs

- IDS [name redacted] ready acknowledgement that my symptoms were real, willingness to consider a Lyme diagnosis, and repeated leading questions

- Significant, though admittedly initially somewhat unstable weight gain; less than a year into treatment, I reached 50kg for the first time in approximately a decade

- The approval of my Income Protection Insurance claim attributing my illness to Lyme and co-infections, by a doctor and psychiatrist whose roles it is to identify false claims.

[redacted]

- Comparison between the two SPECT scans analysed by the same doctor, using the same machine. One scan was taken seven months into treatment, and the other, taken two years later, shows a resolution of hypoperfusion, indicating effective treatment has taken place.

[redacted]

The LLMDs

Quite simply, it is because of these amazing people that I am alive today. Had I left work back in 2012 with no treatment plan, validation, direction or support, I can't imagine that I would have been able to sustain the "live for others" approach for as long as I have.

All of the LLMDs I have mentioned throughout this document are GPs; they are people who at the end of their training chose to use their knowledge by acting as a first point of general medical contact to their communities. They did not choose careers in hospitals that I understand to be rife with politics, and they did not choose the complexity of a specialised role, preferring to instead support those specialists.

And yet, through keeping their fingers on the pulse of their community, and responding appropriately, they have ended up dealing with more politics and greater treatment complexity than I imagine they ever thought possible.

Their detractors would like people to believe that the LLMDs are simply after patients' money – and it's certainly true that their appointments can be expensive. But it's also true that those appointments are usually at least 45 min long, and can also involve significant administrative follow up, including the ordering of PICC supplies for patients, writing new scripts for antibiotics (which can often involve seeking PBS authority) and supplementary medicine between appointments, and frequently reading the of numerous detailed test results.

They also spent time outside of business hours furthering our cause via their Australian Chronic Infectious and Inflammatory Diseases Society (ACIIDS), mentoring others, accepting mentoring themselves, attending conferences, and responding to requests from the media.

As earlier mentioned, one of my LLMDs gave me his personal mobile number and email address so that I could contact him if I had any issues with my PICC while he was on Christmas holidays. Another gave free 15 minute phone consultations to monitor my progress. Two more would go online during appointments to help me find the cheapest supplements of a high quality that they could. One called out of the blue one day between appointments to say she'd been thinking of me, and wanted to know how I was.

Even the LLMDs who have never treated me have helped me; with my permission, my case was discussed at an ACIIDS meeting due to the inconsistency of my improvements.

I was lucky enough to attend the KMF Tick Borne Disease Conferences on behalf of the LDAA in 2013 and 2014, and listened to the LLMD speakers express genuine joy and satisfaction when discussing the recovery of patients. In one memorable case, an LLMD also spoke of his shame at realising he'd previously let his patients down, by referring them off to specialists, and never checking back in with them to ensure their issues were resolved. This LLMD, from a tick endemic area, said many of these patients found no answers from their specialists, and, discouraged, didn't think to return to him. He later realised with deep regret, that had he followed up with them at the time, he would have likely realised much earlier there was an endemic health issue facing his community.

During conference breaks, I often overheard doctors speaking to each other about being labelled 'charlatans' by other medical professionals or being criticised by their colleagues in medical centres for not meeting a daily quota of patients due to the time they spent with their Lyme patients.

I also heard one doctor speak of the stress his commitment to Lyme patients had placed on his family life; his spouse had anticipated life with a GP would involve a relatively stable workload and prestige amongst the local community, only to watch him working all hours of the day and night, and to find that they both exposed to a wide variety of responses from the local people, including ridicule and suspicion.

Lyme patients aren't easy to treat; they can at times become easily confused, forget to follow through on directions they are given, and have been known to misguidedly direct their frustration at their LLMDs or their receptionists. Their bodies' reactions to medications can be unpredictable, severe and therefore risky.

Despite all these obstacles, most LLMDs continue to treat us, and to do so with respect, passion and genuine care.

None of these doctors know me on a personal level, but all of them have done far more for me than anyone who knows, and indeed loves, me (with the exception of Ryan).

I'm sure they have their faults, like everyone, but I believe these people are amongst the best the human race has to offer.

Many LLMDs have found that they not only face negative reactions from colleagues, but also the scrutiny of AHPRA. It is to be expected, of course, that AHPRA would be nervous about GPs effectively taking on the role that IDS' are choosing to sidestep, particularly in treating a disease that the government considers controversial.

However, there is a difference between monitoring, and "*bullying and harassment*". Senators Nick Xenophon and John Madigan believe that AHPRA has crossed the line, inspiring the Medical Complaints inquiry.[5] It is for that reason that I said earlier that "*most* LLMDs continue to treat us" despite obstacles. I know of at least one who has given up, citing fear of repercussions from AHPRA.

Of course, I don't know much about the dealings between LLMDs and AHPRA, other than that there is a vibe of intimidation, and that some LLMDs have been banned from treating Lyme, which seems pretty strange in itself (can you imagine a doctor being barred from treating malaria, for example?!)

What I *do* know, however, is that APHRA seem to have let the review of other doctors slide, with fatal consequences, according to a recent news article. The article reports that Western Health's head of obstetrics, Professor Glyn Teale, made a complaint to AHPRA regarding a doctor at Bacchus Marsh Hospital sending home a patient who haemorrhaged during the delivery of her stillborn child, without identifying a potentially fatal infection, "*but the regulator failed to act for two years".*

Dimitra Dubrow, the patient's lawyer, is quoted as saying "*Our client is devastated about the time it took AHPRA to make its finding, because she questions and thinks about what could have been. All those other babies, all those other lives that could've been saved if the hospital had acted sooner or AHPRA had made its finding sooner."*

Indeed, the article goes on to state that "*In October last year, Health Minister Jill Hennessy revealed that seven of …11 baby deaths* (at the hospital) *could have been prevented*", and that "*Ms Hennessy sacked the board and the management of Bacchus Marsh."*[6]

I obviously have no medical qualifications, nor details regarding the decision making processes AHPRA employees follow, but based on the above, to a layperson such as myself, it appears AHPRA's resources have

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[5] Nick Xenophon, *Senate inquiry into medical complaints regime*, 2 Feb 2016, http://www.nickxenophon.com.au/media/releases/show/senate-inquiry-into-medical-complaints-regime/

[6] Emma Reynolds, '*Most painful thing I've been through': Mothers speak out on horror hospital*, 16 Feb 2016, http://www.news.com.au/lifestyle/health/health-problems/most-painful-thing-ive-been-through-mothers-speak-out-on-horror-hospital/news-story/c7f6487a51cfa79112c885927eb70d5d

been inappropriately allocated, at the expense of the health of Lyme patients, and, more tragically, the lives of newborn babies.

Yes, I have heard two anecdotal stories of Lyme patients being admitted to hospital for severe herxes or potential reactions to medications, but I have never heard of a death resulting from LLMD treatment. I can think of no reasonable explanation for AHPRA's priorities.

Leading American LLMD [name redacted] has been quoted as saying *"In the fullness of time, the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government and virtually the entire insurance industry have colluded to deny a disease."*

It is one of my greatest wishes that should this happen, agencies such as AHPRA will be held to account, and our LLMDs will be recognised for their courage, tenacity, and compassion.

Patient stories

The Australian Lyme community has been both a blessing and a curse in my life – while it has been absolutely amazing to have people I can relate to after 10 long isolated years, exposure to their suffering multiplies my distress.

So, despite the honour of meeting the most courageous, resilient, motivating and caring people I've ever encountered, and witnessing the true grace of human nature that is only revealed in the very worst of circumstances, I began extricating myself their world approximately a year after joining it, and have been almost totally removed a further year.

I'm not sure how many of my Lyme 'family', as I'd come to view them, will be writing their own submissions, nor how detailed those submissions may be, as despite huge excitement at having an opportunity to be heard, recounting our stories comes at a huge mental, emotional and physical price.

For that reason, I'd like to share some stories of other patients, that I was involved in; these have scarred me deeply, and are therefore part of my story, too. I hope they will have an impact on you, also.

Please note: I have altered the name and sometimes the gender of each patient to ensure total protection of their privacy.

"Have you ever heard of Conversion disorder?"

Some patients have seizures so severe (or even periods of unconsciousness), that they are admitted to hospital. To my knowledge, staff very rarely – if ever – accept a Lyme diagnosis as the cause, and very often patients find themselves in a highly vulnerable state, surrounded by people who either believe they are 'faking', or who resentfully dismiss them as having Conversion disorder.

Conversion disorder is commonly described as a functional neurological disorder in which psychological stress is expressed physically. I have no idea why this inspires resentful dismissal - to me, the thought of my psyche being in so much emotional pain that it tried to escape by distracting itself with seizures is horrific.

But anyway, [patient name redacted] is one such patient.

One morning I received a distressed call from [patient name redacted], saying someone had called an ambulance on his behalf the previous evening while he was in a reduced state of consciousness, and he now found himself in a hospital ward. He seemed disorientated and somewhat confused, which is to be expected after these episodes, and also felt betrayed.

He'd become fixated on the fact he'd asked a member of his household to bring him a personal comfort item on their way to work, but they hadn't had time to. After he finished venting to me about all this, he threatened suicide (by the exact same method my brother had died, by horrible coincidence), hung up, and switched off his phone.

Heart racing, I immediately called the ward to notify them of the situation, and that I was on my way. When I finally arrived (the hospital was not my local), [patient name redacted] had calmed down, and tearily apologised for scaring me.

Shortly after this, two members of the Mental Health Team arrived, and asked to interview us both, to assess the level of self harm risk. After listening carefully to our accounts, they reassured us that [patient name redacted]'s frustrations were typical of a patient with a serious chronic illness, and suggested he see a local psychologist who specialises in this area.

[patient name redacted] agreed and we returned to the ward. I kept him company throughout the day, and by early evening, the sound of beeping machines was irritating his noise-sensitive brain, so he asked permission to go outside for a smoke. Being a naturally gregarious person, he soon struck up conversations with fellow smokers, and soon about an hour had passed. I knew the nurses would not appreciate such a long absence, but could see that being around people who treated him normally was vastly improving his frame of mind, so I didn't interfere.

As [patient name redacted] chatted and laughed, an ambulance approached with sirens wailing. Knowing that this noise could set off a seizure, I dived toward his wheelchair to put my hands over his ears, but it was little protection –he launched into a Grand Mal seizure, and his new friends melted off into the shadows, horrified.

At that moment, his nurse came marching out in search of us. He (the nurse) was understandably furious that we'd been gone so long, and at finding [patient name redacted] in such a state. We were whisked back to the ward, and I took my cue to leave, with my tail between my legs.

Before going, I approached the woman I believed to be the Nursing Unit Manager – she certainly had some kind of seniority over the other nurses. I apologised for what had happened, to which she replied, with tight lipped disapproval "*Have you ever heard of Conversion disorder?*"

My heart dropped. Of course I had heard of it, but I couldn't believe this woman, presumably having a scientific mind given her occupation, would attribute [patient name redacted]'s illness to a condition that so clearly contradicted the events of the day.

To recap; [patient name redacted] had been very emotionally distressed in the morning, yet no seizure. [patient name redacted] had been enjoying himself and laughing in the evening, and all hell breaks loose.

I think most people can relate to the feeling of life just draining out of you when faced with ignorance, hatred or something equally as ugly. Imagine that feeling whilst you are as sick and exhausted as you've ever felt, and have experienced the day I've just described. That's why I didn't point out the obvious, but instead found myself saying, with weakened knees "*Do you think that's what [patient name redacted] has?"*

The NUM replied with a significant look "*That's not for me to say*", although clearly she'd heavily implied it.

I'm ashamed to say I left it at that – I didn't have the mental, emotional or physical energy to do otherwise, but that doesn't prevent the shame. I felt I'd let [patient name redacted] down, although I knew I'd shot myself in the foot similarly in the past.

(My local dentist had asked me why I had a my PICC, and when I explained, he said "You shouldn't be doing that – what if you got a serious illness later in life, but had developed a resistance to the antibiotics?!" To which I replied, with self hatred in my heart "I know".)

"We are in the business of saving lives, not ending them, Janice!"

[patient name redacted] is the most incapacitated patient I personally have ever met. The infection seemed to have affected all her systems equally significantly – her brain, her heart, her digestive tract, and God knows what else.

Due to the severity of her illness, she was not often able to travel the distance required to see an LLMD – this was only possible when a fellow patient would make the round trip to take her in their car. Through their informal taxi service, she had managed to see two LLMDs, one of whom referred her to the other, who was more experienced. Both doctors expressed concerns about her ability to return to anything resembling a normal, functional life, even with the very best treatment.

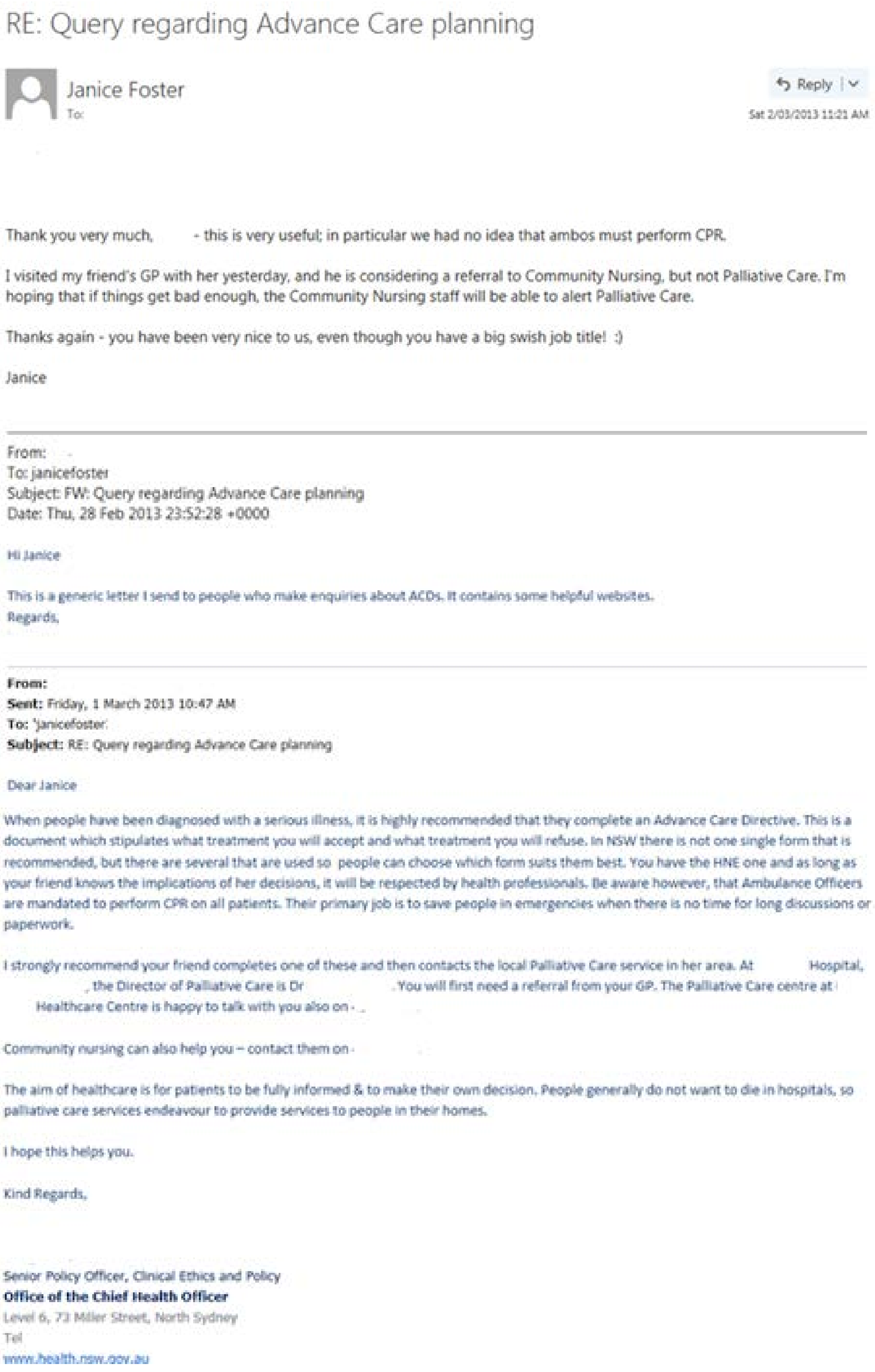
On good days, she was unable to walk without any form of spasticity, and had to rely on a mobility device. On bad days, she was barely able to move at all, and her flatmate was often distressed to come home from work and find [patient name redacted] in almost the exact same position he'd left her in many hours earlier – yes, this meant she was often soiling herself.

[patient name redacted] had had much worse hospital experiences than that of [previous patient name redacted] previously described, and although she didn't want to commit suicide, she wanted to allow "nature the opportunity to take its course", when she periodically lost consciousness. She also wanted a friend to be present at the time, as the thought of dying alone is pretty horrible.

Having been bereaved by suicide myself, I wasn't entirely comfortable with this, but I was even less comfortable with preventing someone with [patient name redacted]'s quality of life the right to choose this route, just because of my own discomfort.

So, I started doing some research, and discovered that people in NSW are entitled to write an Advanced Care Directive (ACD), stipulating their wishes regarding medical care should they be so incapacitated as to be unable to express them themselves.

In February 2013, I contacted NSW Health for more information, as per the below email trail:



RE: Query regarding Advance Care planning

Janice Foster
To:

Sat 2/03/2013 11:21 AM

Thank you very much, - this is very useful; in particular we had no idea that ambos must perform CPR.

I visited my friend's GP with her yesterday, and he is considering a referral to Community Nursing, but not Palliative Care. I'm hoping that if things get bad enough, the Community Nursing staff will be able to alert Palliative Care.

Thanks again - you have been very nice to us, even though you have a big swish job title! :)

Janice

From:
To: janicefoster
Subject: FW: Query regarding Advance Care planning
Date: Thu, 28 Feb 2013 23:52:28 +0000

Hi Janice

This is a generic letter I send to people who make enquiries about ACDs. It contains some helpful websites.
Regards,

From:
Sent: Friday, 1 March 2013 10:47 AM
To: 'janicefoster
Subject: RE: Query regarding Advance Care planning

Dear Janice

When people have been diagnosed with a serious illness, it is highly recommended that they complete an Advance Care Directive. This is a document which stipulates what treatment you will accept and what treatment you will refuse. In NSW there is not one single form that is recommended, but there are several that are used so people can choose which form suits them best. You have the HNE one and as long as your friend knows the implications of her decisions, it will be respected by health professionals. Be aware however, that Ambulance Officers are mandated to perform CPR on all patients. Their primary job is to save people in emergencies when there is no time for long discussions or paperwork.

I strongly recommend your friend completes one of these and then contacts the local Palliative Care service in her area. At Hospital, , the Director of Palliative Care is Dr . You will first need a referral from your GP. The Palliative Care centre at Healthcare Centre is happy to talk with you also on -

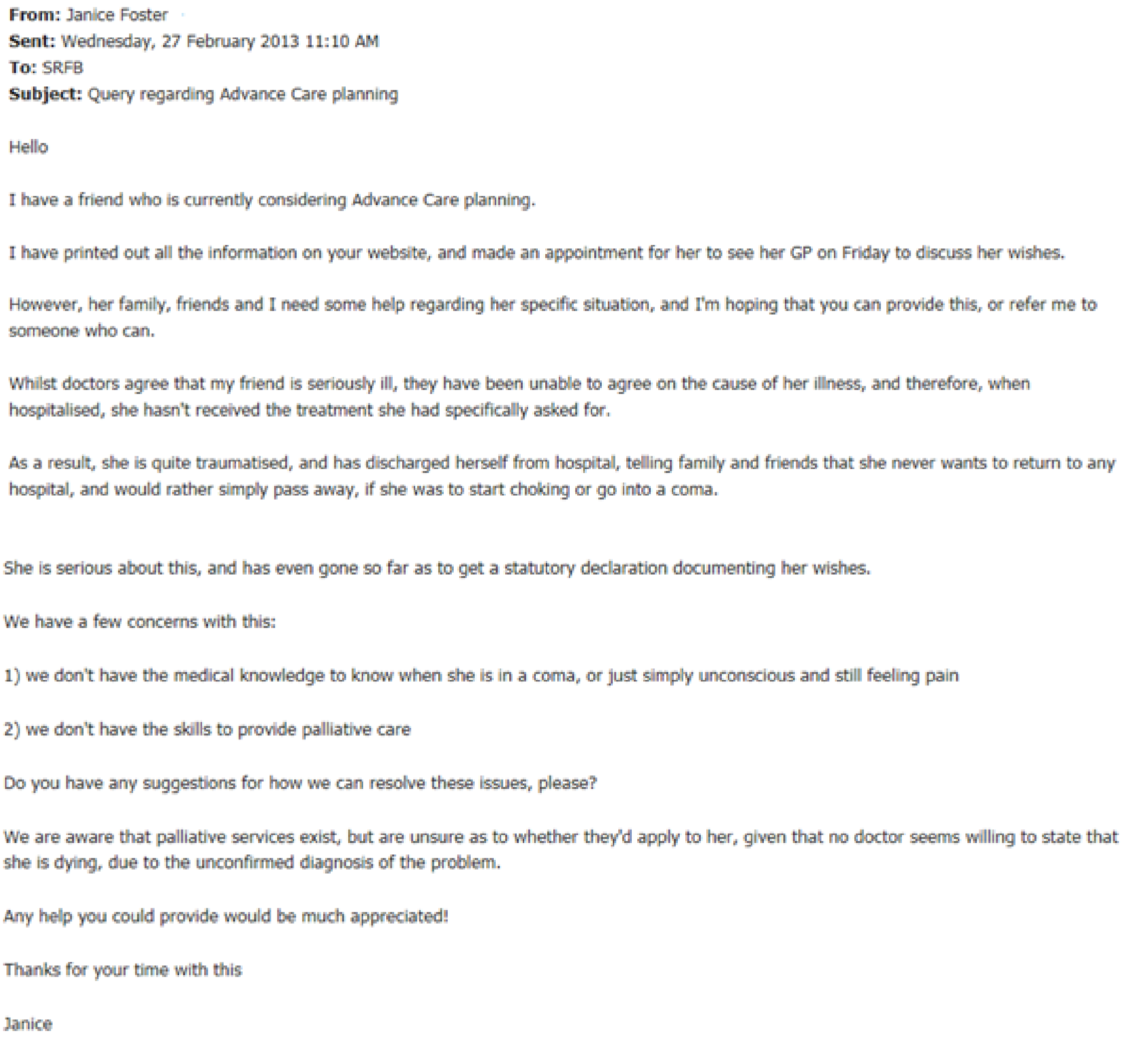
Community nursing can also help you – contact them on

The aim of healthcare is for patients to be fully informed & to make their own decision. People generally do not want to die in hospitals, so palliative care services endeavour to provide services to people in their homes.

I hope this helps you.

Kind Regards,

Senior Policy Officer, Clinical Ethics and Policy
Office of the Chief Health Officer
Level 6, 73 Miller Street, North Sydney
Tel
www.health.nsw.gov.au



From: Janice Foster
Sent: Wednesday, 27 February 2013 11:10 AM
To: SRFB
Subject: Query regarding Advance Care planning

Hello

I have a friend who is currently considering Advance Care planning.

I have printed out all the information on your website, and made an appointment for her to see her GP on Friday to discuss her wishes.

However, her family, friends and I need some help regarding her specific situation, and I'm hoping that you can provide this, or refer me to someone who can.

Whilst doctors agree that my friend is seriously ill, they have been unable to agree on the cause of her illness, and therefore, when hospitalised, she hasn't received the treatment she had specifically asked for.

As a result, she is quite traumatised, and has discharged herself from hospital, telling family and friends that she never wants to return to any hospital, and would rather simply pass away, if she was to start choking or go into a coma.

She is serious about this, and has even gone so far as to get a statutory declaration documenting her wishes.

We have a few concerns with this:

1) we don't have the medical knowledge to know when she is in a coma, or just simply unconscious and still feeling pain

2) we don't have the skills to provide palliative care

Do you have any suggestions for how we can resolve these issues, please?

We are aware that palliative services exist, but are unsure as to whether they'd apply to her, given that no doctor seems willing to state that she is dying, due to the unconfirmed diagnosis of the problem.

Any help you could provide would be much appreciated!

Thanks for your time with this

Janice

By mid-April, [patient name redacted] had spoken to both her LLMD and local GP about Advance Care Planning (ACP) and its implications, then written an ACD.

My understanding is that between April and August, the ACD was presented to ambulance officers on several occasions, relayed to the Emergency Department of her local hospital, and then ignored. (I say “my understanding”, because I wasn’t personally present.)

Anyway, it so happened that on 6 August 2013, [patient name redacted] was again rushed to the Emergency Department, while I was in the local area.

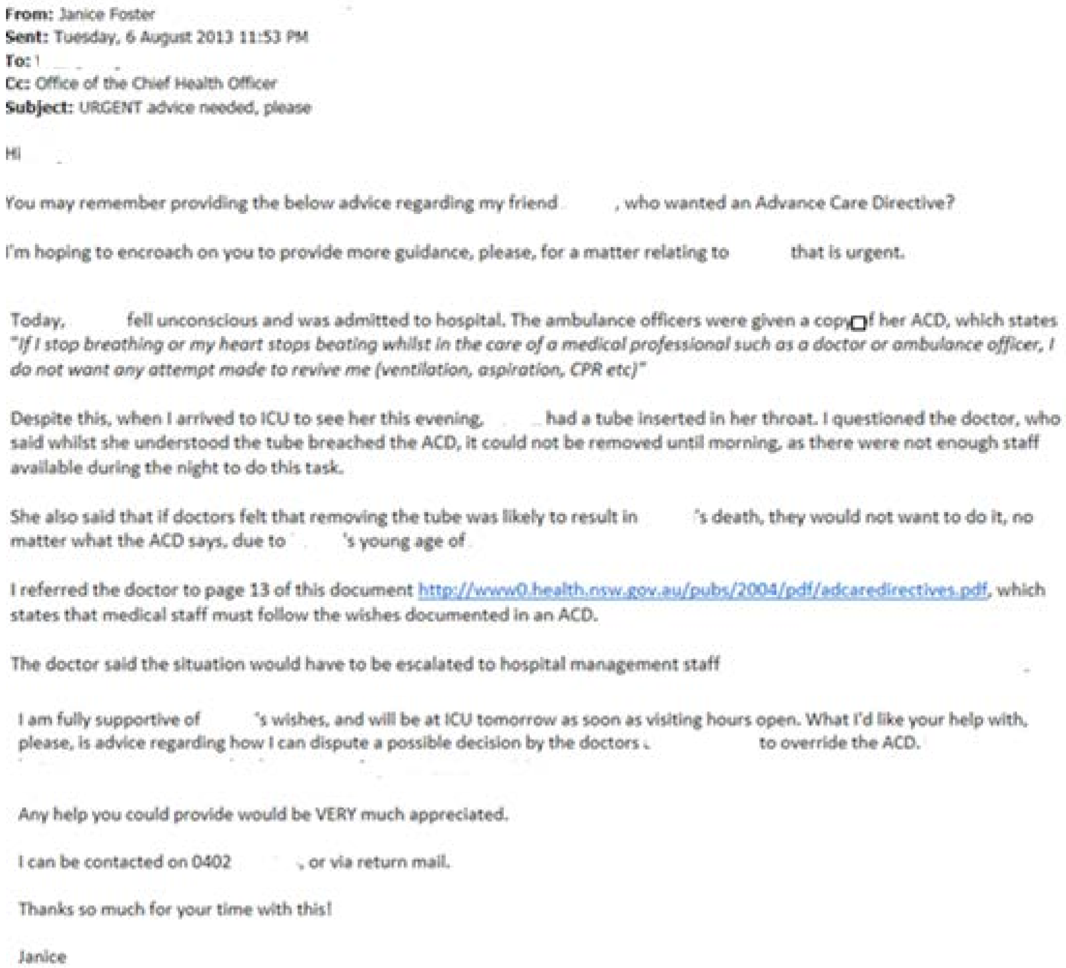
I arrived at ICU armed, as always, with print outs of information about ACDs from the NSW Health website. To my dismay, I saw that [patient name redacted], still unconscious, had been intubated. I requested that the tubes be removed immediately, in line with her wishes. I was told by a doctor that whilst she understood that the intubation breached [patient name redacted]’s ACD, there weren’t enough staff available on night shift to remove it.

I expressed serious doubt that it was in any way acceptable to break the law just because “it’s outside business hours”, and also questioned the effort involved in removing the tube, given patients in ICU have their own dedicated nurse.

The doctor then told me that no one would want to remove the tube, as [patient name redacted] might die, and she was too young to die. (Again, not an acceptable reason – [patient name redacted] well knew the consequences of what she had requested, and, being over 18, had every right to ask it. And yes, [patient name redacted] is young, but that's kind of the point – if she was 95, she wouldn't have to dread drawn out suffering for potentially further decades.)

I was told that the situation would be escalated to the CEO in the morning. The distinct impression I got was that the doctors hoped by that time the intubation would no longer be needed, so the point would become moot.

The rest of the night passed in a blur. I finally arrived home at about 11:30pm, and immediately sent my Senior Policy Officer contact the below email.



From: Janice Foster
Sent: Tuesday, 6 August 2013 11:53 PM
To:
Cc: Office of the Chief Health Officer
Subject: URGENT advice needed, please

Hi

You may remember providing the below advice regarding my friend , who wanted an Advance Care Directive?

I'm hoping to encroach on you to provide more guidance, please, for a matter relating to that is urgent.

Today, fell unconscious and was admitted to hospital. The ambulance officers were given a copy of her ACD, which states *"If I stop breathing or my heart stops beating whilst in the care of a medical professional such as a doctor or ambulance officer, I do not want any attempt made to revive me (ventilation, aspiration, CPR etc)"*

Despite this, when I arrived to ICU to see her this evening, had a tube inserted in her throat. I questioned the doctor, who said whilst she understood the tube breached the ACD, it could not be removed until morning, as there were not enough staff available during the night to do this task.

She also said that if doctors felt that removing the tube was likely to result in 's death, they would not want to do it, no matter what the ACD says, due to 's young age of

I referred the doctor to page 13 of this document http://www0.health.nsw.gov.au/pubs/2004/pdf/adcaredirectives.pdf, which states that medical staff must follow the wishes documented in an ACD.

The doctor said the situation would have to be escalated to hospital management staff

I am fully supportive of 's wishes, and will be at ICU tomorrow as soon as visiting hours open. What I'd like your help with, please, is advice regarding how I can dispute a possible decision by the doctors to override the ACD.

Any help you could provide would be VERY much appreciated.

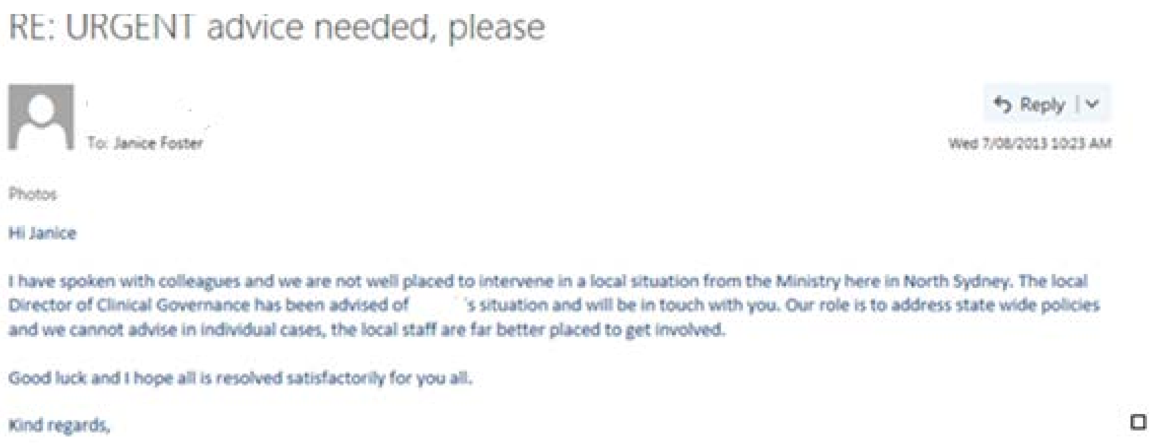
I can be contacted on 0402 , or via return mail.

Thanks so much for your time with this!

Janice

You'll notice that I cc'd in the Office of the Chief Health Officer. I never received any form of response from them.

I did, however, receive the following response from the Senior Policy Advisor:


RE: URGENT advice needed, please

To: Janice Foster

Wed 7/08/2013 10:23 AM

Photos

Hi Janice

I have spoken with colleagues and we are not well placed to intervene in a local situation from the Ministry here in North Sydney. The local Director of Clinical Governance has been advised of 's situation and will be in touch with you. Our role is to address state wide policies and we cannot advise in individual cases, the local staff are far better placed to get involved.

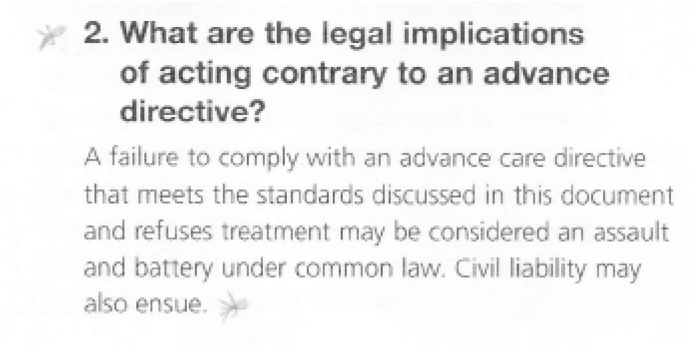
Good luck and I hope all is resolved satisfactorily for you all.

Kind regards,

The following morning, I arrived at ICU to find [patient name redacted] still unconscious, and that no progress had been made on this matter, nor any timeframe estimated for when this would occur. A doctor told me “*Our CEO is very busy, you know.”*

At some point, I remember a different doctor sneering at me *“Janice. We are in the business of* saving *lives, not ending them*”, despite the fact that hospital staff (to my knowledge) had in the past never done much to help [patient name redacted] other than monitor her until she was stabilised, then ship her off home as soon as she was well enough to leave, only for the cycle to start again.

I offered the doctors my print out of the ‘*Questions about interpreting and acting on advance care directive instructions’* document, referring in particular to the following:


2. What are the legal implications of acting contrary to an advance directive?

A failure to comply with an advance care directive that meets the standards discussed in this document and refuses treatment may be considered an assault and battery under common law. Civil liability may also ensue.

However, they refused to look at it, and in fact told me that the ACD wasn’t binding, as a solicitor hadn’t signed it. I knew that was incorrect, but again, they just dismissed me.

I considered calling the police, but was faced with the dilemma that so many Lyme patients experience – if I cause trouble, will this mean all-out war between the Lyme community and the public health system? Do I have the right to take that risk?

I can’t remember the circumstances leading up to me speaking to the Senior Policy Advisor, quite possibility it was just the ongoing lack of urgency or concern demonstrated in the above comment. This may have also been coupled with the fact that the Director of Clinical Governance did not get in contact with me as expected.

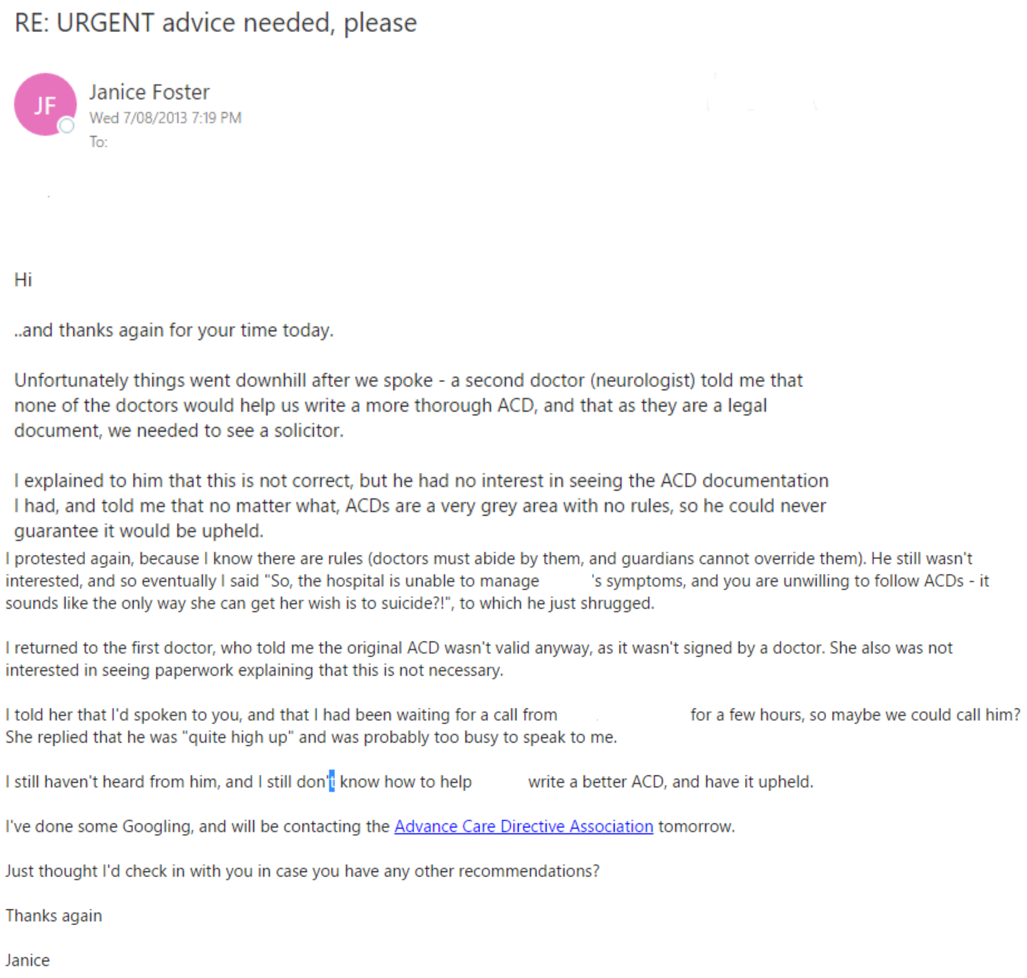
In any case, I ended up speaking to her, and she was very empathetic, but unable to help. Somehow I ended up speaking with someone else, who may have been the Director of Clinical Governance, or not. All I can remember is that it was a woman, and her response was basically along the lines of "*Bummer. We're still training our staff in ACDs, so yeah…things go wrong.*"

This obviously didn't address the highly unprofessional and dismissive behaviour that went along with the doctors' lack of knowledge about ACDs, their refusal to read documentation by their own employer relating to ACDs, and their apparent total comfort in doing so without fear of repercussion (that comfort was clearly justified, based on this woman's response).

The only other contribution the woman made was to say that I should be careful about the wording of the ACD, as some doctors weren't assisting their patients in ensuring the wording was clear enough to cover the majority of scenarios that may occur in a seriously ill patient. She offered to send me out some information regarding that. I asked if it would include contact details of doctors who *did* know how to write effective ACDs; she kind of dodged the question, and I was too wrung out to push her on it.

(Sure enough, when the pamphlet arrived, it contained very generic information and was effectively useless.)

As for how the rest of that day panned out, I can't clearly remember. All I have to guide me is this final email to the Senior Policy Advisor, to which I can't find a response.



RE: URGENT advice needed, please

JF
Janice Foster
Wed 7/08/2013 7:19 PM
To:

Hi

..and thanks again for your time today.

Unfortunately things went downhill after we spoke - a second doctor (neurologist) told me that none of the doctors would help us write a more thorough ACD, and that as they are a legal document, we needed to see a solicitor.

I explained to him that this is not correct, but he had no interest in seeing the ACD documentation I had, and told me that no matter what, ACDs are a very grey area with no rules, so he could never guarantee it would be upheld.

I protested again, because I know there are rules (doctors must abide by them, and guardians cannot override them). He still wasn't interested, and so eventually I said "So, the hospital is unable to manage 's symptoms, and you are unwilling to follow ACDs - it sounds like the only way she can get her wish is to suicide?!", to which he just shrugged.

I returned to the first doctor, who told me the original ACD wasn't valid anyway, as it wasn't signed by a doctor. She also was not interested in seeing paperwork explaining that this is not necessary.

I told her that I'd spoken to you, and that I had been waiting for a call from for a few hours, so maybe we could call him? She replied that he was "quite high up" and was probably too busy to speak to me.

I still haven't heard from him, and I still don't know how to help write a better ACD, and have it upheld.

I've done some Googling, and will be contacting the Advance Care Directive Association tomorrow.

Just thought I'd check in with you in case you have any other recommendations?

Thanks again

Janice

I never ended up contacting the Advance Care Directive Association, because at that stage I pretty much had a nervous breakdown.

[patient name redacted]'s condition has continued to deteriorate, and for the majority of the last three years, she has lived in a care facility.

Waiting to die

[patient name redacted] is also one of the most seriously ill patients (yes, it's mainly extremely ill patients that feature in these stories; their degree of debilitation coupled with the lack of context and support given to loved ones by the general medical community often results in said loved ones pretty much abandoning the patients, whose care is then shared amongst healthier, and far more empathetic, patients).

Among other symptoms, she has seizures, mobility issues, a dementia-like condition and severe fibromyalgia. Her suffering is relentless, and follows a predictable periodic cycle in which what was previously highly distressing, becomes absolutely unbearable.

[patient name redacted] can feel the worst of the cycle coming on, and faces them with fear and dread. Each time, she is sure she's going to die (as is any witness outside the medical profession, that I've ever discussed her with). She feels very cold to the touch, in all seriousness like she's spent a couple of hours in a fridge.

Anyway, one Winter evening, [patient name redacted] had had enough. She had very little support, was unable to access regular treatment from an LLMD, and the thought of facing this macabre rollercoaster indefinitely was unthinkable.

Due to the research I'd done for [name of patient in last story redacted], [patient name redacted] was aware that legally, anyone who found her in an incapacitated state had a responsibility to call an ambulance, regardless of her wishes. As with [name of patient in first story redacted] she saw her trips to hospital as a way to prolong her agony, in an unsympathetic and unfriendly environment.

So she left her house with her mobility aid and mobile phone, and disappeared into nearby bushland, hoping to die there. She texted myself and her other friends to tell us what she'd done, thank us for our help, and say goodbye.

Her friend group immediately swung into action – we contacted each other to discuss what the best course of action might be. Our immediate thought was to call the police, who would be able to trace her general vicinity based on her mobile signal, but we were reluctant to betray the trust she had in us. The likely outcome would be that she'd feel even more alone, and would just do it again when the next cycle came, but this time without telling us.

As you can imagine, the responsibility of our knowledge was a huge burden, and, as chronically ill people ourselves, the stress began to take a toll on us also. We pretty much became frozen by despair, indecision, and fatigue on all kinds of levels.

The thought of her alone and extremely vulnerable, surrounded by frigid darkness, convinced that there was no mercy to be found in our community/allegedly first world health system, just willing death, was the stuff nightmares are made of. Not to mention the fear that there might be someone else out there in the bush who could do virtually anything to her.

As the chilly night wore on, we were at least reassured by the fact that she was texting each of us intermittently. Her messages were often very jumbled and confused, and at times she accused us of betraying her and forcing her into the action she'd taken. The thought of our last conversation being a negative one was horrible, and I read the messages with heart pounding.

Somehow she made it through the night, and although I can't remember precisely what happened (my memory of that time is dominated by the horror of that night; what came next was overshadowed), at some point she got in contact with her Social Worker, and eventually returned home.

"Can you give me permission to clean her up?"

This is another story about [name of patient in last story redacted]. On one occasion, she was extremely unwell, but had not lost consciousness nor the ability to strongly express a desire to avoid hospital. That said, she was scared, and wanted some company. I myself was too unwell to help that night, but our friend [friend's name redacted] agreed to make the trip.

By the time he arrived at her house, she had wet herself, and although still conscious, and responding to questions about going to hospital, she was not giving an intelligible response to his offer of cleaning her up. Being male, he felt uncomfortable doing so, for fear of sexual connotations. He called me to discuss the dilemma, given we both had experience in toileting [patient name redacted], and had even previously done it together. We agreed that I would send him a text confirming that I had previously witnessed him assisting [patient name redacted] in using the toilet at her request, and on those grounds, as her close female friend, I assumed consent for him to clean her up.

Bear in mind that both [friend's name redacted] and I were very sick – even the medical experts who assessed my Income Protection Insurance claim had agreed I was not in a fit state to sit behind a bloody office desk doing a job with no significant implications, yet here I was trying to negotiate my way around balancing the requests of a very distressed and seriously ill friend, with avoiding legal trouble for another seriously ill friend. And [friend's name redacted] was even sicker than I was; often when I saw him, he had sweat running down his gaunt face, and a prominent vein sticking out of his forehead as he grappled to deal with the responsibilities we were facing.

We should never have been put in this situation – nor the previously mentioned [patient name redacted] story - by our society, but many patients do find themselves in this position, as healthy loved ones find it all too overwhelming, and leave. Being patients ourselves, we cannot leave the hell that is 'Lymie life', so we try to at least improve each others' situations by offering support.

Unfortunately this can then result in increased sickness in ourselves, due to the stress, but we are caught between a rock and a hard place; either we stress because getting involved takes so much out of us, or we stress because of the helplessness and guilt of being unable to assist another. The drive to assist is also increased by the isolation of our situation, and the desire to be a contributing member of the community again.

It is primarily because of this dilemma that I became completely burned out, and, at the urging of my LLMDs, removed myself from the Lyme community, reasoning that if I didn't know what was happening, I wouldn't need to continually push myself beyond my limits. That meant not only stepping back from individual patients, but also the political work and volunteer organisations. This decision was truly a bitter pill to swallow; the LDAA in particular had a snowballing workload due to the increasing awareness of Lyme, and had to manage the accounts of unfiltered distress they received from patients and carers, whilst dealing with their own illness, and the strain of providing detailed responses to the increasingly aggressive Lyme deniers.

Difficult as it was, I believe it was the right decision as even now, almost 18 months after the last of these stories occurred, reliving them through this chapter has caused me to vomit in my mouth.

The government's ineffectual response to the Australian Lyme situation

The apparent lack of government concern and unresponsiveness to the pleas of Lyme patients, has been extremely damaging to the Lyme community, and certainly the most significant hurdle to gaining recognition and effective treatment.

Often when there is ongoing conflict with a government, people begin to speculate about conspiracy theories. I've personally never been one for conspiracy theories – I've always thought that government employees are just normal people like everyone else, who just want to do their job well then go home; it seems paranoid to assume Machiavellian motivations on their part.

Over time though, it has occurred to me that "normal people like everyone else" often engage in unsavoury behaviour at work. Even in the most poorly paid jobs I've ever had, there's always been someone who tried to sabotage others to big note themselves, ridiculed others to take the heat off themselves when they make a mistake, or avoided promoting anyone with a higher level of competence than themselves to avoid being 'found out'.

So, while I don't believe there has been a deliberate or widescale conspiracy, I believe there is sufficient evidence that conspiracy has taken place through inappropriate behaviour nonetheless:

Scientific studies – blatant disregard and cherrypicking

The LDAA site references evidence that Borrelia has been present in Australia for over 55 years[7]. This information has been present on the LDAA site since at least 2013, and has been part of discussions that activists within the Lyme community have been attempting to have with the government for decades.

Yet, I can't find any evidence of a government response to this apparently one-sided conversation. Even if the relevant government authorities have reason to discount this evidence, surely they should respond with their professional interpretation of said evidence? A one-sided plea for help based on scientific evidence should, in all common sense, be a discussion that they join respectfully and with all the professional diligence that their occupations (should) demand.

(I note with some cynicism that since this inquiry was initiated, a report summarising the evidence has finally been published.[8] One of its authors is employed by the Australian Rickettsial Reference Laboratory, although he notes that he is "…*co-authoring this article in his personal capacity and in his capacity as an adjunct academic at Central Queensland University*." Another ARRL employee is recognised for "…*her assistance with the evaluation of reported molecular findings in studies reviewed by this paper."* The Director and founder of the ARRL is Prof Graves, who has given evidence at the Brisbane and Sydney hearings. Just prior to the Sydney hearing, Prof Graves stated in an interview with ABC Great Southern Radio that he, too, had recently been

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[7] Lyme Disease Association of Australia, *Evidence of Borrelia in Australia*, http://www.lymedisease.org.au/evidence-of-borrelia-in-australia/

[8] Chalada et al*, Is there a Lyme-like disease in Australia? Summary of the findings to date*, March 2016, http://www.sciencedirect.com/science/article/pii/S2352771416300039

involved in a scientific paper. He was the peer reviewer for 'Does Lyme exist in Australia?'[9] which was co-authored by Dr Lum and published shortly before the Sydney hearing.)

Borrelia was originally found in native animals in 1959, and the first case was formally reported in a human in 1982. At the conclusion of this 1982 report, which focuses primarily on a single patient, it is stated that "*Six cases of ECM (Erythema chornicum migrans) have been diagnosed by Hunter Valley dermatologists over the last 12 months, which indicates that the aetiological agent is well established in the area, and more cases of Lyme arthritis may be expected.*"

One would think that this is sufficiently alarming for further investigation, but I can find no record of any such action, even in the face of continually mounting evidence, including a reported EM rash on a patient in the NSW South Coast in 1985, who consulted his doctor after receiving multiple tick bites, and at least one case reported on the NSW Central Coast in 1986, referred to in a 1989 article in the Australian Veterinary Journal that reported cattle in Camden, NSW, returning positive serology testing for suspected Lyme disease.

A letter to the Medical Journal of Australia in 1991 entitled 'Detecting the cause of Lyme disease in Australia', stated that Borrelia spirochetes were identified in 42% of the 167 native ticks processed in a study.

The letter stated "*These findings indicate that some species of tick often responsible for human and animal tick bites in this country commonly harbour Borrelia species spirochetes. On structural and antigenic grounds these microbes are likely to be the aetiological agents of Lyme disease in Australia.*"

Eventually in 1994, two major studies into the likelihood of Borrelia in Australia were published:

1) Researchers from Westmead Hospital, NSW, performed a study funded by a National Health and Medical Research Council (NHMRC) grant, to investigate whether Australian ticks carry Borrelia burgdorferi.

   The study (commonly known as the 'Russell and Doggett' study) found that they did not, but was flawed for the following reasons:

   - A large percentage of the ticks involved were larvae. Ticks in this developmental stage have recently left the egg. It's not until they have their first meal of blood that larvae moult into the next stage; that of nymph. As Borrelia is transmitted to ticks via the blood of an infected host, it's very unlikely that the larvae have had the opportunity to contract the bacteria.

   - The ticks were only tested for the American species of the bacteria (B. burgdorferi senso stricto) and not for others that were known at the time; the European species B. garinii and B. afzelii. This was a significant oversight, given the heritage of modern Australia, the number of animals that have been imported from Europe, and the migratory patterns of birds from the Northern Hemisphere.

   These findings were also controversial in that whilst "*spirochete-like organisms*" were identified in the fed ticks (ie bacteria shaped in a form common to Borrelia), they did not deem these significant.

   It should also be noted that this study has often been used to dispute the presence of Lyme in Australia, despite the fact that the ticks were collected from a 2000km stretch of NSW coastline – a

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[9] Collignon et al, Does Lyme disease exist in Australia?, https://www.mja.com.au/journal/2016/205/9/does-lyme-disease-exist-australia

small area considering the Australian coastline is more than 35 000km in length. This also means that the tick populations of other ecological regions were overlooked.

In fact, it is the sole study referred to in the NSW Health's Lyme disease factsheet, as at 15 March 2016.

2) In the early 1990s, researchers from the Microbiology Departments of NSW's Royal North Shore Hospital and Newcastle University had collaborated to investigate their suspicion that the incidence of locally- acquired Lyme disease was much higher than previously reported. As a result, a hotline was set up so that suspected Lyme patients could volunteer to participate in a study.

   The researchers were not put off by Russell and Doggett's findings, stating *"These negative results have not deterred our research as one of us (BJH) regularly sees clinical cases of LB (Lyme Borrelia) acquired in Australia"*

   This new study revealed that 20% of the 1024 participants reporting Lyme-like symptoms received a 'positive' result on a Western Blot diagnostic test. Of those, 90% were 'positive' due to the European species of Borrelia, B. garinii or B. afzelli.

   Only 10% had evidence of B. burgdorferi senso stricto, the sole species that Russell and Doggett used as a basis for their study.

Despite the flaws of the Russell and Doggett study, this study has been cherrypicked for government responses, to the exclusion of the numerous other studies I have briefly touched upon. I've never heard a justification by the government as to how this single study overrides all the others, which leads me to the obvious conclusion that it's just the one that delivered the outcome the government wants to hear.

It is ludicrous that the government have been able to blatantly cherrypick information to suit their purposes for literally decades, and do so apparently unchallenged by anyone other than the Lyme community. Where is the government's due diligence? Where is their duty of care? What have the Office of Health Protection been doing all this time?

While writing this chapter of my submission, I came across the online details of someone involved with Australian research into the presence of Borrelia. I noted that this person belonged to groups called 'Beyond Workplace Bullying Australia', 'Coping with the Trauma of Workplace Bullying' and 'Dignity for all Australian Public Servants'.

This person had promoted a petition related to the above topics. In sharing the petition, the person wrote "*…research has shown most bullies in the workplace are promoted or rewarded*". This corresponds with my own earlier musings in this chapter (written prior to finding this information) that in workplaces "*…there's always been someone who tried to sabotage others to big note themselves, ridiculed others to take the heat off themselves when they make a mistake, or avoided promoting anyone with a higher level of competence than themselves to avoid being 'found out.'"*

I would like to make it clear that I am not claiming that this person was bullied at any stage directly as a result of their involvement in Lyme-related research, but I do believe it's a possible indicator of a culture in which this could occur. I will not speculate further, but ask the Senate to consider this be an appropriate avenue of investigation. If a toxic culture exists amongst the Australian scientific community at the expense of the health of its citizens, it needs to be addressed. People's health – and indeed their lives – are not pawns to fuel office power games.

I would also like to draw your attention to the first report of human babesiosis in Australia, in 2012[10], which resulted in death of the patient. Babesiosis is an infection often found in Lyme patients; I myself was clinically diagnosed with it on the basis of herx reactions to an antibiotic challenge.

I believe in addition to the studies outlined above, this should have been impetus for the appropriate area of the government to move forward proactively, rather than be dragged reluctantly into further investigation by patients and their political representatives.

Finally, I note that NSW Health's submission (number 457) states: *"NSW Health supports the pursuit of scientifically rigorous research into known and suspected tick-borne and other vector-borne diseases. To achieve this, research study proposals should be competitively assessed and funded through the usual medical research funding bodies, such as the National Health and Medical Research Council and the Australian Research Council".*

As demonstrated by the Australian Rickettsial Reference Laboratory's (ARRL) submission (number 459), this advice is out of touch with reality: "*There is actually very little research being undertaken into tick-transmitted pathogens in Australia. This is because very little funding has been made available for this purpose. This is part of a wider trend in Australia where research on any infectious disease is poorly supported compared to research on other medical problems such as cancer, cardiovascular conditions, mental health [including dementia], etc, which are now seen as the main medical problems in Australia. An application to the National Health and Medical Research Council [NHMRC] to fund research into possible tick-transmitted infections would almost certainly not be funded, due to perceived low priority and limited fund availability. Thus researchers are loath to invest their time and effort into a application that is unlikely to be successful.*"

I assume that as the Chief Medical Officer's liaison point for Lyme and Lyme-like illness, Dr Gary Lum would have had some input into NSW Health's submission. As earlier mentioned, Prof Graves is the Director of the ARRL. He's also a spokesperson for the Royal College of Pathologists Australasia. Both men were members of the government's 2013-2014 Clinical Advisory Committee into Lyme Disease (CACLD). It is disappointing that during the CACLD's meetings, this very significant roadblock raised by the ARRL in their submission was apparently not discussed, let alone addressed in any way.

Cherrypicking of information on the government's Lyme disease factsheet

I believe the cherrypicking of information on the NSW Health Lyme disease factsheet[11] as at 15 March 2016 to be significant.

For example, on the topic of transmission, the document states:

"Lyme disease is transmitted following the bite of a tick that is infected with the Borrelia bacterium"
and *"Lyme disease is not spread from person to person".*

This fails to address all of the studies that have found evidence of other methods of transmission.[12] Surely even if the government has some doubt as to the validity of these studies, they should either err on the side of caution and mention the risk as a possibility, or outright state why they believe the outcomes of those studies to be inaccurate.

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[10] Senanayake et al, *First report of human babesiosis in Australia*, The Medical Journal of Australia, 2012, https://www.mja.com.au/journal/2012/196/5/first-report-human-babesiosis-australia

[11] NSW Health, *Lyme disease fact sheet,* http://www.health.nsw.gov.au/Infectious/factsheets/Pages/lyme_disease.aspx

[12] Lyme Disease Association of Australia, *Lyme Disease Transmission*, http://www.lymedisease.org.au/transmission/

In regards to evidence of locally acquired Lyme, the sheet states: *"In the 1990s, 12,000 ticks were collected from different parts of NSW and were tested for* Borrelia *bacteria. No evidence of* Borrelia *infection could be found in any of the ticks collected."* I refer you back to my earlier observation, that the only study the government seem to publicly acknowledge, is the one that serves their purpose.

In reference to diagnosis, the sheet states *"Diagnosis of any infectious disease requires a combination of clinical experience and assessment by the doctor and understanding of the lab tests and their limitations. Laboratory results are rarely definitive"* – but hang on, isn't the government's trump card that they have insufficient pathological evidence of Borrelia in Australia?! Oh wait – they've covered themselves by then saying "*When tests are done in places where a disease is rare or absent (for example, Lyme disease in Australia), many positive tests will be falsely positive."*

The document fails to mention on what scientific basis this assumption of "*false positive*" should be made.

Furthermore, the author's statement that Lyme disease in Australia is "*rare or absent*", contradicts the document's earlier statement that *"...locally-acquired Lyme borreliosis cannot be ruled out*".

If it can't be ruled out, then it can't be deemed absent. And if no one is assessing the volume and accuracy of diagnoses (which they are not - the document later states vaguely "*When these cases have been followed up in the past, the cases have been found to have acquired the infection overseas*" and also that "*Lyme is not notifiable in NSW*"), then on what grounds can it be called 'rare'?

And, for that matter, why have cases "*in the past*" been followed up on patients with a history of overseas travel? There are plenty of patients, myself included, who became ill without ever leaving Australia.

The document goes on to state that "*Lyme disease is most commonly diagnosed by a screening test called ELISA and this is then confirmed using a western blot test. Both of these tests detect antibodies that are produced by the immune system of someone with Lyme disease."* Well, yes, but the Lyme community has expressed detailed and appropriately referenced concerns about the efficacy of ELISA testing[13] for years, and these remains unaddressed.

So far as treatment goes, the document simply states "*Most cases of Lyme disease can be treated successfully with a few weeks of antibiotics".* This information was presumably sourced from the Infectious Diseases Society of America (IDSA), which has been very influential – yet also very controversial - from 2000-2015.

As the IDSA guidelines don't allow for the possibility of chronic Lyme disease, they have caused significant concern in America, resulting in subsequent legislation in volumes that imply that a short term antibiotic regime is not successful for "*most cases."*

In New York, doctors using long-term antibiotic treatment were investigated by the Office of Professional Medical Conduct. In 2002, the New York Assembly discussed this issue. The related documentation recognises the existence of CLD by stating "*Patients in whom* [Lyme] *disease is not caught early and who are not treated adequately can progress to chronic disease with infection of the central nervous system…*" The Assembly voted

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[13] Bakken et al *Interlaboratory Comparison of Test Results for Detection of Lyme Disease by 516 Participants in the Wisconsin State Laboratory of Hygiene/College of American Pathologists Proficiency Testing Program, 1996, pg 7,* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC229622/pdf/350537.pdf
Coulter et al, *Two-Year Evaluation of Borrelia burgdorferi Culture and Supplemental Tests for Definitive Diagnosis of Lyme Disease*, 2005, http://jcm.asm.org/content/43/10/5080.full
Wojciechowska-Koszko et al, *Serodiagnosis of borreliosis: indirect immunofluorescence assay, enzyme-linked immunosorbent assay and immunoblotting*, 2011, https://www.ncbi.nlm.nih.gov/pubmed/21258869
Lyme Disease Association of Australia, *Why is Lyme disease controversial?*, http://www.lymedisease.org.au/transmission/

that “*insurance companies and the Office of Professional Medical Conduct cease and desist from targeting* [these] *physicians.”*[14]

Also in 2002, the Rhode Island General Assembly passed a ‘doctor protection law.’ This law ruled that doctors couldn’t be disciplined for treating CLD with long-term antibiotics.[15] Five other states have since introduced similar legislation.[16] (Six states out of 50 mightn’t seem many, but Lyme disease is far more common in some states than others, due to varying tick populations.)

In 2003, the Rhode Island General Assembly introduced legislation requiring health insurers to cover long-term antibiotic treatment for CLD.[17] The legislation was trialled for a year. In 2004, it was made permanent.[18]

In 2010, the Commonwealth of Massachusetts passed legislation formally allowing long-term antibiotic therapy for Lyme disease.[19]

Concerns were raised regarding the motives of the IDSA panel who wrote the guidelines. An American anti-trust investigation followed. At its conclusion, Attorney-General Richard Blumenthal stated "*My office uncovered undisclosed financial interests held by several of the most powerful IDSA panelists. The IDSA's guideline panel improperly ignored or minimised consideration of alternative medical opinion and evidence regarding chronic Lyme disease, potentially raising serious questions about whether the recommendations reflected all relevant science.”*[20]

Until early 2016, however, the IDSA guidelines remained on the American government’s National Guidelines Clearinghouse (NGC) database, which is described as *“...an Internet-based resource that contains evidence-based clinical practice guidelines and related documents...an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation and use.”*[21]

However, the NGC's criteria for guidelines changed. It undertook the Institute of Medicine's new 'Standards for Developing Trustworthy Clinical Practice Guidelines.’[22] In 2015, the IDSA guidelines were reviewed against these new criteria. The guidelines were found to be non-complaint, and were subsequently removed from the database.[23]

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[14] State of New York, *Assembly Resolution 2155*, 2002, http://www.lymeinfo.net/nyresolution.html

[15] State of Rhode Island General Assembly, *Lyme disease diagnosis and treatment act*, 2002, http://webserver.rilin.state.ri.us/PublicLaws/law02/law02159.htm

[16] Legislative Council of the State of California, *Assembly Bill No. 592, Chapter 304*, 2005, http://www.leginfo.ca.gov/pub/05-06/bill/asm/ab_0551-0600/ab_592_bill_20050922_chaptered.pdf
State of Connecticut, *Public Act No 09-128*, 2009, https://www.cga.ct.gov/2009/act/Pa/pdf/2009PA-00128-R00HB-06200-PA.PDF
The State of New Hampshire, HB 295, 2011, https://legiscan.com/NH/text/HB295/id/135807
General Assembly of the State of Vermont, *No 134, An act relating to Lyme disease and other tick-borne illnesses*, 2014, http://www.leg.state.vt.us/docs/2014/Acts/ACT134.pdf
Maine State Legislature, *An Act To Improve Access to Treatments for Lyme Disease*, http://www.mainelegislature.org/legis/bills/bills_127th/billtexts/HP028901.asp

[17] State of Rhode Island General Assembly, *Lyme disease diagnosis and treatment Act*, 2003, http://webserver.rilin.state.ri.us/PublicLaws/law03/law03113.htm

[18] State of Rhode Island General Assembly News, *House passes Lyme disease bill*, 2004, http://www.rilin.state.ri.us/pressrelease/Lists/PressReleaseData/DispForm.aspx?ID=969

[19] The Commonwealth of Massachusetts, *Section 12DD Administration of long-term antibiotic therapy upon diagnosis of Lyme disease,* 2010, https://malegislature.gov/Laws/GeneralLaws/PartI/TitleXVI/Chapter112/Section12DD

[20] Office of the Attorney-General, *Attorney General’s Investigation Reveals Flawed Lyme Disease Guidelines Process, IDSA Agree to Reassess Guidelines, Install Independent Arbiter*, 1 May 2008, http://www.ct.gov/ag/cwp/view.asp?a=2795&q=414284

[21] Agency for Healthcare Research and Quality, *What is the National Guideline Clearinghouse?,* ahttps://info.ahrq.gov/app/answers/detail/a_id/230/~/what-is-the-national-guideline-clearinghouse%E2%84%A2%3F

[22] The National Academies of Sciences, Engineering and Medicine, *Standards for Developing Trustworthy Clinical Practice Guidelines*, accessed Aug 2016, http://www.nationalacademies.org/hmd/Reports/2011/Clinical-Practice-Guidelines-We-Can-Trust/Standards.aspx

[23] L Johnson, *IDSA Lyme guidelines removed from NGC; ILADS guidelines still there*, accessed Aug 2016, https://www.lymedisease.org/idsa-guidelines-removed-ngc/

The only treatment guidelines for Lyme disease currently on the NGC are those of the International Lyme and Associated Diseases Society (ILADS). The ILADS guidelines recommend long-term antibiotic treatment when short term regimes have proven insufficient.

The authors say "*…we moved away from designating a fixed duration for antibiotic therapy and instead encourage clinicians to tailor therapy based on the patient's response… We not only recommend that clinicians perform a deliberate and individualised assessment of the potential risks and benefits of various treatment options before making their initial selection, we also recommend careful follow-up because this allows them to adjust therapy as circumstances evolve. This patient-centred approach should reduce the risk of chronic illness due to inadequate antibiotic therapy.*"[24]

The NSW Health Lyme disease factsheet is an accurate reflection of the government's approach to the Lyme issue – messy, contradictory, demonstrating a bias in presenting information, and not committing to any plan to either validate or disprove claims of locally acquired Lyme. It's an absolute disgrace, as is the fact that patients like myself have spent years raising these points, to no avail.

Inconsistent government department response to locally acquired Lyme

This is one of the things that puzzles me most – while according to the NSW Health Lyme disease factsheet, as at 15 March 2016 "*there is little evidence*" of locally acquired Lyme, some patients have been receiving worker's compensation payments for Lyme acquired through local tick bites.

The first case of this I heard of was in 2012 – from memory it was the groundskeeper of a resort on the NSW North Coast, who had documented the bites. I heard about it on A Current Affair, I think, but can't find any Google results for it.

I'm also aware of NSW Parks and Wildlife rangers who have Workcover approved claims for Lyme acquired on the job. Some Parks and Wildlife branches have actually been holding tick bite prevention talks for their staff.

How and why is it possible, that this degree of contradiction is happening?

Lack of transparency

It is difficult to get an impression other than that the government has done everything it can to ignore the Lyme issue, or at least avoid publicly acknowledging it.

In April 2011, in response to the increasing number of Australian patients (some of whom had never been overseas) receiving positive Lyme diagnoses based partly on blood test results from specialist overseas laboratories, NSW Health secretly gathered a panel of specialists in public health, epidemiology, infectious diseases, rickettsial diseases and entomology.

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[24] International Lyme and Associated Diseases Society, *ILADS Guidelines are now summarised on the National Guideline Clearinghouse Website*, accessed Aug 2016, http://www.ilads.org/ilads_news/2015/ilads-treatment-guidelines-are-now-summarized-on-the-national-guideline-clearinghouse-website/

Representatives of the Lyme community were not invited.

The panel's existence and subsequent findings weren't openly communicated; it wasn't until the LDAA obtained the details via the Freedom of Information Act, that the Lyme community became aware of it. This strikes me as very strange; given the Lyme community have been consistently calling for attention, why would NSW Health conceal this action from them, until forced to do otherwise?

Shortly afterward, a now outdated NSW Health factsheet on Lyme disease reflected the opinion of the panel: *"While there is little evidence that Lyme disease is caused by Australian ticks, there may be other infections carried by Australian ticks which may cause an infection which is similar to Lyme disease. These infections remain poorly characterised."*

Despite this finding, no research was undertaken to characterise this "*infection similar to Lyme disease*". The issue was just dropped without explanation. Apparently the government has no duty of care to its citizens, despite the existence of the Office of Health Protection, who describe their role as follows:

"The mission of OHP, in partnership with key stakeholders, is to protect the health of the Australian community through effective national leadership and coordination and building of appropriate capacity and capability to detect, prevent and respond to threats to public health and safety"[25]

Apathetic responses - general

During 2011-2012, [name redacted], then President of the LDAA, made numerous attempts to organise meetings with government representatives including Federal Health Minister Tanya Plibersek, NSW Health Minister Jillian Skinner and NSW Director of Health Protection Dr Jeremy McAnulty, but did not receive favourable responses.

However, when Lyme patients [name redacted] and [name redacted] headed the first Australian Lyme protest outside the NSW Health headquarters in September 2012, [name redacted] was immediately invited upstairs to speak to Dr Jeremy McAnulty. I remember [name of previous LDAA President redacted] standing at the protest, shrugging her shoulders and saying "So it turns out to get attention you just need to scream!"

While I am grateful for [name redacted]'s opportunity to be heard, it is extremely disappointing that the government did not find it fit to respond to professional correspondence from a registered organisation, choosing not to engage until virtually compelled to, by chronically ill patients who have very little energy for such activity.

Unfortunately, not much in the way of practical help came of the McAnulty meeting, nor, in my opinion, the Clinical Advisory Committee (CACLD) of 2014. I say that not just as a patient, but also as the Administrator of the Lyme Patient Consultative Group, which was established by the LDAA to liaise directly with Dr Lum.

Early on in the lifespan of the CACLD, the RCPA, represented at the CACLD by Prof Graves, released a poorly referenced Position Statement, that included the phrase "*Australian ticks are not thought to carry the Borrelia spp. that can cause Lyme Disease*."

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[25] The Department of Health, *Office of Health Protection (OHP),* http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-about.htm

(I note – again with cynicism - that since I obtained that quote from the statement in early March 2016, the statement has been updated[26], despite having previously had a scheduled review date of February 2017. The quote in question has been removed.)

Why exactly any statement was appropriate, given that the CACLD had just begun to investigate the possibility of locally acquired Lyme, ostensibly with an open mind, I do not know.

It doesn't seem to be a reactive response to people asking for it; the RCPA actually launched a media campaign to promote it. You can view evidence of the campaign by visiting the LDAA Master References List,[27] and searching on the phrase "*Sample of RCPA's media campaign to promote their Position Statement.*"

It appears, however, that Dr Lum either did not try to have the RCPA remove the statement, or was ineffective in doing so.

I urge anyone who has not read it, to review the LDAA's excellent Counter Argument to the RCPA Position Statement,[28] which is referenced in appropriate detail. You'll also note that this document lists the scientific studies relating to Borrelia in Australia that are usually ignored; this is attempt at stimulating a response of the "one sided discussion" I referred to earlier. It is a great pity that LDAA volunteer staff, who at the time were almost exclusively chronically ill, found themselves in the situation of having to provide this counter argument, whilst dealing with the other many burdens placed on them.

In the meantime, however, it is my understanding that Dr Lum found the time to contact a small patient advocacy group [name of advocacy group redacted], to ask them to remove a petition they had underway for government attention on Lyme, effectively as a goodwill gesture, given the committee was underway. The [name of advocacy group redacted] agreed, and retracted their petition immediately. The RCPA's Position Statement remains online.

In fact, NSW Health's submissions refers to it in glowing terms: *"NSW Health supports the Royal College of Pathologists Australasia (RCPA) position statement Diagnostic Laboratory Testing for Borreliosis ('Lyme Disease' or similar syndromes in Australia and New Zealand (number 1/2014, February 2014, which provides excellent background and direction…"*

My own opinions on the government's response are supported by the manner in which Senator Madigan held Dr Gary Lum to account for the lack of practical outcomes of the CACLD, in the 2015 NSW Parliamentary hearing. Dr Lum seemed to have no real answers for why he did not persevere through certain hurdles, and why the patient community has experienced no real benefit as a result.

My understanding is that it is only thanks to the ongoing advocacy work of the LDAA, and the persistent aggressive stance of Senator Madigan and MP Jill Hall that this Senate inquiry is occurring.

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[26] Royal College of Pathologists Australasia, *Position Statement - Diagnostic Laboratory testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand*, http://www.rcpa.edu.au/Library/College-Policies/Position-Statements/Diagnostic-Laboratory-testing-for-Borreliosis-Lyme

[27] Lyme Disease Association of Australia, *Master References List*, http://www.lymedisease.org.au/references/

[28] Lyme Disease Association of Australia, *Counter argument to the Royal College of Pathologists Australasia Position Statement on Diagnostic Laboratory testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand*, April 2014, http://www.lymedisease.org.au/wp-content/uploads/2010/11/20140408ResponsetoRCPAPositionStatementFinal.pdf

The initiation of this inquiry has inspired some aggressively defensive responses from the medical community. In particular, I would like to focus on the behaviour of Dr Michael Gannon. At the time of the Perth inquiry hearing, Dr Gannon has the Western Australian President of the Australian Medical Association.

On the morning of the hearing, Dr Gannon told the media that "*This inquiry is an unholy waste of money, the only possible recommendations from this parliamentary inquiry are more research, and that research is already being done.*"[29] He also stated that patients were "*pretending to have Lyme disease*"[30] and that their treating doctors were *"charlatans."*[31]

This bizarre behaviour, of course, illustrates the need for the following Terms of Reference of the inquiry:

"methods to reduce the stigma associated with Lyme-like illness for patients, doctors and researchers"

and

"the signs and symptoms Australians with Lyme-like illness are enduring, and the treatment they receive from medical professionals"

At the subsequent Canberra inquiry hearing, the following interaction took place:

"*CHAIR: If you could also take on notice whether you responded to the president of AMA's comments in Western Australia who said that we were an 'unholy waste of taxpayers' money', which seems to conflict with your evidence.*

Dr Lum: The department has not responded to comments made by the president of the WA AMA branch.

CHAIR: Would you, given what you have just said about the value of this inquiry?

Dr Lum: We have not discussed it."

Senator Reynolds also questioned Dr Lum as follows:

"Senator REYNOLDS: You never got on the phone to them and you have not talked to the president of the AMA or to any of their senior medical staff? You have sent an update and that is the limit of what the department has done.

Dr Lum: That is part of our regular communication framework.

Senator REYNOLDS: But you have never got on the phone, consulted or had a meeting.

Dr Lum: I did not personally get on the telephone with the president of the AMA, no.

Senator REYNOLDS: If you could take that on notice. It surprises me that you have never personally engaged with the AMA"

It does not surprise me – although it does frustrate me – that Dr Lum has not had any meaningful interactions with the AMA regarding Lyme. It may not be part of the "*regular communication framework*", but surely comments as subjective – and arguably – defamatory, as Dr Gannon's should prompt a response, regardless of

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[29] Briana Shepard*, Lyme disease: Five people with symptoms suicided in WA in past three years, inquiry hears,* 14 Apr 2016, http://www.abc.net.au/news/2016-04-14/lyme-disease-parliamentary-inquiry/7328140

[30] Seven News, *Senate inquiry into Lyme disease*, https://www.youtube.com/watch?v=-3M7eh2bpSQ

[31] ABC News, *Lyme disease Australian debate*, 14 Apr 2016, https://www.youtube.com/watch?v=Ge8TOVw_HQw&app=desktop

normal protocol.

In fact, at the same hearing, Dr Lum gave every indication that he understood the importance of his role in the Lyme debate, reminiscing that on *"21 January 2013, I remember distinctly, at 4 pm, the Chief Medical Officer, Professor Chris Baggoley, coming to me, putting both hands on my shoulders and saying, 'Gary, I have a very important task for you."*

That comment, to me, sounds like one of someone who should recognise that Dr Gannon's comments warranted going beyond *"the regular communication framework."*

I assume that Dr Lum still has not spoken to the AMA regarding Dr Gannon's comments, as just one day after the inquiry's Interim Report was published, Dr Gannon again spoke publicly about the inquiry in derogatory terms. This time, his view was apparently shared by the AMA, as it was documented on their Western Australian website.[32]

Despite previously claiming that "…*the only possible recommendations from this parliamentary inquiry are more research, and that research is already being done",* this time Dr Gannon stated without apology or clarification, *"We have always agreed that more research is needed into what the patients are really suffering from. An expensive Senate Inquiry to reach this conclusion was entirely unnecessary."*

He also stated that: "*The Senate inquiry into Lyme disease has unearthed nothing new and has only resulted in a waste of time and resources."*

He goes on to say that

"*The recommendation that there be a taxpayer-funded advertising campaign to "…develop education and awareness strategies" for the prevention of tick bites would be an even greater waste of money.*

The proud history of important Senate Inquiries will only be weakened if weak inquiries like this one are allowed to continue.

It is sad to see well-meaning and appropriately motivated Senators and the Australian Senate as a whole being reduced this.

There have been tears and emotion and the medical profession has been attacked by a range of individuals and support groups, but there has been no light shed on this issue."

and

""I would urge the Senate to put this Inquiry to bed when the Senate reconvenes after the election. There are better things to spend taxpayer funds on…"

Dr Gannon was promoted to AMA National President, on the basis of a member election, just weeks later.[33]

In the lead up to the Sydney hearing, the defensive and aggressive statements from some members of the medical profession intensified. Unfortunately, given the deadline for this submission, I don't have time to locate and quote them, so I will instead refer to LDAA President Sharon Whiteman's opening statement at the Sydney hearing:

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[32] Australian Medical Association (WA), Senate Inquiry into Lyme Disease a waste of time and resources, 6 May 2016, http://www.amawa.com.au/senate-inquiry-into-lyme-disease-a-waste-of-time-and-resources-ama-wa/

[33] Australian Medical Association, *Dr Michael Gannon elected new AMA President*, 29 May 2016, https://ama.com.au/media/dr-michael-gannon-elected-new-ama-president

"For obvious reasons, I will first address the overwhelming media assault earlier this week. I lost count at 10 publications, mostly because I was so busy responding to sick Australians, helping them to understand that, while seemingly overwhelming, and power in numbers, these voices are actually the minority. One could be forgiven for thinking that the Australian Medical Association and others represented in these articles were part of a media and marketing juggernaut organisation, all colluding to skew the focus with this message. They set their timing to win, to do the most harm, and I ask: to whom? The sick patients that they are meant to protect, that under oath they have committed to protect and to serve and to do no harm. I ask you: what of any of these named articles this week were aligned with that? Not a single one. It will have done further harm to the 21 people who reported that they are suicidal as part of the submissions they have made to this committee."

I would also like to draw the Committee's attention to an event that occurred at the Canberra hearing. After this event, I spoke to Senator Reynolds, who, although the instigator of it, had not recognised the significance of what occurred. To understand it, you need an indepth understanding of the Lyme community that the senators have not had the time or resources to develop. I would therefore like to put it into context for the committee.

During his questioning of Dr Lum, Senator Madigan bought up the issue of patients who have contracted Lyme disease overseas, but upon returning to Australia, have experienced lengthy delays in diagnosis, and even then, inability to access appropriate treatment. To illustrate his point, he stated:

'"…some people I have met who had been confined to a wheelchair, after having been to overseas clinics they are now re-engaged in society and are working. Having had some of the treatments such as antibiotics—I think, it is Dr Horowitz in the US—they have come home and are back in the community... I know for one lady, $90,000 is what she spent."

While Senator Madigan did not mention the patient he was referring to by name, the specific circumstances immediately identified her to the patient community as [name of previous LDAA President redacted] whose story has been publicly shared many times.

Dr Lum, by his own admission, knows [name of previous LDAA President redacted]; in her role as a senior member of our community she has had significant interaction with the government, and was in fact the CACLD's sole Patient Representative. He should therefore also have immediately recognised and validated her story, but instead, Senator Madigan observed, he "*baffled us with bullshit*".

This led to tearful indignation from the audience, which was acknowledged by Senator Reynolds, who said "*Dr Lum, you have some of the people behind you and they are absolutely in tears. Just turn around and have a look at them. These are the people you have not yet talked to in person. I appreciate that you came to Perth, but I tell you what: their faces, their tears, their words and their head shakes tell us what you are saying is simply not the case."*

What the Hansard transcript then captures is Dr Lum blustering "*I believe that* [name of previous LDAA President redacted] *particularly, who I know, and others sitting in the audience today are suffering. I know, and I understand the concerns that they have. I have heard them, but we have to go with where the evidence is."*

There is no explanation offered as to why [name of previous LDAA President redacted]'s case is not "evidence", and again, the audience are incredulous.

Senator Reynolds picks up on this, and replies "*I am not quite sure whether you wilfully misunderstood what my colleagues have said, and I think clearly that the audience thinks that you have".* It is only then that Dr Lum is forced to say "*I acknowledge full well that I have many colleagues who are in a situation where, when patients present to them, like* [name of previous LDAA President redacted] *and like others, they will not necessarily believe their stories."*

There are two points I'd like to make regarding this event.

1) Firstly, the senators and anyone outside the Lyme community may not have been aware of the specifics of [name of previous LDAA President redacted]'s case, and the impossibility that Dr Lum would not have enough familiarity with it to immediately identify the case in question and respond to Senator Madigan accordingly.

   His failure to do so indicates to me two possibilities. The first is that he "wilfully misunderstood" the line of questioning, as alluded by Senator Reynolds.

   If this is the case, I suggest it casts doubt over Dr Lum's objectivity and often-declared commitment to assisting the patient community.

   The second possibility is that Dr Lum simply didn't recognise [name of previous LDAA President redacted]'s case. If so, then given their level of previous interaction, I bring into question his commitment to the role of the Department of Health's liaison with the Lyme community.

2) What the Hansard transcript didn't capture, and what the senators might not have been aware of, is that when Senator Reynolds demanded that Dr Lum turn around and face the patients, he was forced to look straight into the face of the very patient whose experience he was denying; [name of previous LDAA President redacted] was sitting directly behind him.

   With a sigh, Dr Lum said "Hi [name of previous LDAA President redacted]."

   [name of previous LDAA President redacted] met his eye with and replied in an even tone "Hi Gary."

   BAM! To me, that moment sums up the experience of patients, their resulting activism, and the government's response. Blustering from Dr Lum until he was cornered, followed by reluctant, unapologetic acknowledgement, which was met with quiet dignity by [name of previous LDAA President redacted].

Finally, I believe the below interaction from the Sydney hearing sums up the apathy of the government in relation to the patient community and their plight:

"Senator REYNOLDS: Just to clarify, you spent four years discussing something that you have repeatedly said does not exist here in Australia at all, and you have not yet looked at anything else in that whole time that has come up. I know I am not a doctor, but I think what you have just said to us is that this committee has spent four years reaffirming the fact that you do not think that there is classic American Lyme disease here but have done nothing yet—in four years—to expand the search out to European or Australian tick-borne bacteria that we have had evidence exists here in Australia.

Dr Lum: As I said, the use of the word 'discussion' is taking it a bit too far. There was no discussion; I was providing updates.

Senator REYNOLDS: I feel like I am being flung down the rabbit hole into Oz here."

Apathetic responses – formal complaints

Given that it appeared the government wasn't going to address Dr Gannon's comments proactively, I decided to lodge a complaint with the Health Care Complaints Commission (HCCC) myself.

I referred specifically to what I believed to be breaches of the Australian Medical Board's Code of Conduct. I also made mention of the fact that I first attempted to resolve my complaint with the AMA's national headquarters. However, they referred my complaint to Dr Gannon's staff. When I expressed concern that this was a conflict of interest, they ignored me. I've never heard back from them since.

I sent my complaint to the HCCC on 27 April. When I hadn't had a response by 8 June, I emailed their dropbox. I didn't get a response from that either, so on 10 June I emailed the assessor dealing with another complaint of mine, regarding Dr Brad McKay (more on that later.) On 14 June I received an email from that assessor, stating that the complaint did not sit in her area, but that I "should receive a response shortly."

On 25 July, I again emailed the assessor to say I still hadn't received a response. She provided me with the name of the assessor responsible for the complaint. On 26 July, I emailed him, but got no response. On the 28 July, I found the assigned assessor's phone number online, and left him a voicemail message. He emailed me to say that he'd referred the issue to the AHPRA that very day, and that I'd hear back from AHPRA within 2 weeks. I asked the reason why it had taken so long for any action to be taken, but didn't get a response. I never heard from him again.

On 12 August, I finally heard from AHPRA; for some reason they were unable to access the hyperlinks I'd included in my original complaint, and wanted me to re-send them. I provided them immediately.

On 11 October, I received a letter from AHPRA stating that after assessment, it was decided that "*no further action*" would be taken, and that "*This matter is now closed.*"

The other complaint I had made to the HCCC, was regarding an article by Dr Brad McKay.[34] The article, titled '*The great Australian Lyme conspiracy*' was published approximately a month prior to the first Senate hearing. It contained a number of inaccuracies, and, I believe, a distinctly condescending tone. I have outlined some examples below.

- *"Lyme disease is real, but there's no scientific proof it's occurring in Australia*"

As earlier mentioned, there are numerous studies relating to the presence of Borrelia, covering ticks, animals and humans. Dr McKay's article was published on 16 March 2016. The analysis of these studies[35] that I previously referred to was "*Accepted 19 March 2016, Available online 7 April 2016.*" I am therefore unsure what Dr McKay's source is relying on when making such a definitive statement. Even the article analysing the studies was more circumspect, stating "*…no study to date has definitively identified the presence of a* Borrelia *species infecting humans that have a locally acquired Lyme-like syndrome*

I presume he was simply relying on the Russell and Doggett study, and note that the photo of a tick accompanying the article was credited to Doggett himself.

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[34] McKay, *The great Australian Lyme conspiracy*, http://www.news.com.au/lifestyle/health/health-problems/the-great-australian-lyme-conspiracy/news-story/c5137170015f20db705febcf56223af6

[35] Chalada et al, *Is there a Lyme-like disease in Australia? Summary of the findings to date*, http://www.sciencedirect.com/science/article/pii/S2352771416300039

Many Australians are convinced that Lyme disease from tick bites exists here, but Dr Brad McKay says there's no scientific evidence to support that claim. Picture: Stephen Doggett

- *"Borrelia is the cause of Lyme disease and this bacteria is transmitted to humans via tick bites in North America and Europe."*

This statement is also misleading. According to the European Centres for Disease Control and Prevention, Borrelia is also endemic in temperate areas of Asia – something even the NSW Health Lyme disease factsheet acknowledged - and "…*and its geographic distribution is ever-increasing."*[36]

There are also multiple scientific studies offering evidence of other transmission methods.[37].

This is a moot point anyway; given that the origin of livestock imported during the establishment of modern Australia and the flight paths of migratory birds could well explain how ticks from such areas could reach Australia, as is discussed in Karen Smith's detailed and heavily researched document '*Lyme Disease: A Counter Argument to the Australian Government's Denial*.'[38]

- *"In desperation, she consulted Dr Google and quickly diagnosed herself with Lyme. She read internet forums and learned about a "Great Australian Lyme Conspiracy", where regular doctors don't even believe Lyme exists, but she felt hopeful when she discovered the name of a charismatic Lyme practitioner".*

I have a number of concerns regarding this. Firstly, I find the tone very condescending. Many Lyme patients research their symptoms online, of course they do, as doctors often are unable to offer them answers, effectively forcing their hands. In my experience of the Lyme community, I believe this patient's alleged self diagnosis of Lyme is uncommon; certainly people come to believe it's a possibility, that's why they then seek out confirmation of an LLMD.

The "Great Australian Lyme Conspiracy" is in quotation marks; but there is no clarification as to exactly who Dr McKay quoting. I've never heard that phrase, much less with the fanfare of having each word capitalised.

I Googled it, and in the first three pages of results, which date back to 2012, there is no mention of the term at all. Lyme patients often communicate via private forums, granted, but many have public blogs. An article

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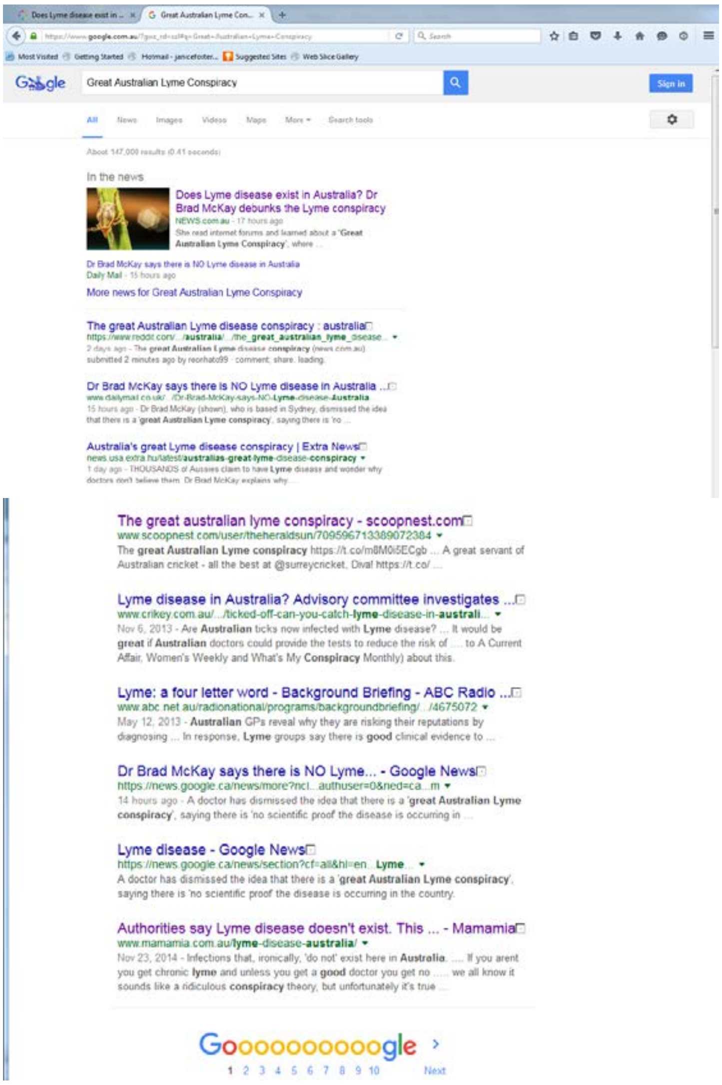
[36] European Centre for Disease Control and Prevention, *Factsheet for health professionals*, http://ecdc.europa.eu/en/healthtopics/emerging_and_vector-borne_diseases/tick_borne_diseases/lyme_disease/factsheet-health-professionals/Pages/factsheet_health_professionals.aspx

[37] Lyme Disease Association of Australia, *Lyme Disease Transmission,* http://www.lymedisease.org.au/transmission

[38] Smith, Lyme disease: *A Counter Argument to the Australian Government's Denial*, http://www.lymeaustralia.com/counter-argument-k-smith.html

written by one patient, Amara Campbell, appears on the first page of results, with no mention of the phrase.



Great Australian Lyme Conspiracy

About 147,000 results (0.41 seconds)

In the news

Does Lyme disease exist in Australia? Dr Brad McKay debunks the Lyme conspiracy
NEWS.com.au - 17 hours ago
She read internet forums and learned about a '**Great Australian Lyme Conspiracy**', where ...

Dr Brad McKay says there is NO Lyme disease in Australia
Daily Mail - 15 hours ago

More news for Great Australian Lyme Conspiracy

The great Australian Lyme disease conspiracy : australia
https://www.reddit.com/.../**australia**/.../the_**great**_**australian**_**lyme**_disease...
2 days ago - The **great Australian Lyme** disease **conspiracy** (news.com.au) submitted 2 minutes ago by neonhato99 · comment; share; loading...

Dr Brad McKay says there is NO Lyme disease in Australia ...
www.dailymail.co.uk/.../Dr-Brad-McKay-says-NO-**Lyme**-disease-**Australia**
15 hours ago - Dr Brad McKay (shown), who is based in Sydney, dismissed the idea that there is a '**great Australian Lyme conspiracy**', saying there is 'no ...

Australia's great Lyme disease conspiracy | Extra News
news.usa.extra.hu/latest/**australias**-**great**-**lyme**-disease-**conspiracy**
1 day ago - THOUSANDS of Aussies claim to have **Lyme** disease and wonder why doctors don't believe them. Dr Brad McKay explains why ...

The great australian lyme conspiracy - scoopnest.com
www.scoopnest.com/user/theheraldsun/709596713389072384
The **great Australian Lyme conspiracy** https://t.co/m8M0i5ECgb ... A great servant of Australian cricket - all the best at @surreycricket, Diva! https://t.co/ ...

Lyme disease in Australia? Advisory committee investigates ...
www.crikey.com.au/.../ticked-off-can-you-catch-**lyme**-disease-in-**australi**...
Nov 6, 2013 - Are **Australian** ticks now infected with **Lyme** disease? ... It would be **great** if **Australian** doctors could provide the tests to reduce the risk of ... to A Current Affair, Women's Weekly and What's My **Conspiracy** Monthly) about this.

Lyme: a four letter word - Background Briefing - ABC Radio ...
www.abc.net.au/radionational/programs/backgroundbriefing/.../4675072
May 12, 2013 - **Australian** GPs reveal why they are risking their reputations by diagnosing ... In response, **Lyme** groups say there is **good** clinical evidence to ...

Dr Brad McKay says there is NO Lyme... - Google News
https://news.google.ca/news/more?ncl...authuser=0&ned=ca...m
14 hours ago - A doctor has dismissed the idea that there is a '**great Australian Lyme conspiracy**', saying there is 'no scientific proof the disease is occuring in ...

Lyme disease - Google News
https://news.google.ca/news/section?cf=all&hl=en...**Lyme**...
A doctor has dismissed the idea that there is a '**great Australian Lyme conspiracy**', saying there is 'no scientific proof the disease is occuring in the country.

Authorities say Lyme disease doesn't exist. This ... - Mamamia
www.mamamia.com.au/**lyme**-disease-**australia**/
Nov 23, 2014 - Infections that, ironically, 'do not' exist here in **Australia**. ... If you arent you get chronic **lyme** and unless you get a **good** doctor you get no ... we all know it sounds like a ridiculous **conspiracy** theory, but unfortunately it's true ...

I speculate that Dr McKay's purpose in using quotation marks and capitalisation is to imply that patients are using this term. The implication, in my opinion, makes patients seem ridiculous.

I'm not sure what the relevance of the LLMD's "charisma" is. None of the LLMDs I've visited could be described as charismatic, bless their hearts. They are way too busy focusing on the complexity of my condition, working together to further their knowledge, undertaking overseas training and building mentorships with more experienced LLMDs, to participate in any popularity contests.

- *"She sent her blood overseas…to receive a positive diagnosis of Lyme disease from an unaccredited lab."*

Unaccredited by whom? We have heard throughout the inquiry that the labs in question are all accredited in their country of origin. Surely he doesn't expect overseas laboratories to seek Australian accreditation?

- *"Lyme activists will tell you that NATA-accredited labs don't detect Borrelia because their machines aren't sensitive enough to pick it up. The truth is that unaccredited labs aren't specific enough, and tend to deliver positive results for Borrelia whether you've got Lyme disease or not."*

Again, no source is noted. I have been very active in the Lyme activism in the past, and I've never heard anyone use an explanation along such childishly simplistic lines. Earlier in this submission I've provided a link to the LDAA's page outlining their concerns with Borrelia testing in Australian labs, which has nothing to do with "*insensitive machines*".

I remind the Committee that we have repeatedly heard throughout the inquiry that NATA accreditation is only required to access Medicare benefits; it does not mean that the testing is inaccurate.

- *"My patient was told that Borrelia was all through her body, eating her joints and rotting her brain"*

That wording sounds a bit melodramatic, granted, but it has some basis in reality. Again, NSW Health's own Lyme Disease factsheet, as at 15 March 2016, states:

"In later stages of Lyme disease the infection spreads through the bloodstream and can cause infection in the brain and membranes surrounding the brain (meningoencephalitis) and infection in or around the heart (endocarditis, myocarditis or pericarditis). The disease can also cause inflammation of joints and cause joint pain and long-term neurological involvement"

- *"Panicked by this horrific news and desperate to get her old Lyme-free life back, she obediently commenced treatment"*

Again, this strikes me as very condescending and belittling. I feel for this patient, and wonder how she reacted to reading her story, publicly related in such a manner. Given his role as host on the TV show 'Embarrassing Bodies', it's a reasonable expectation that Dr McKay would be more aware than most of the importance of publicly relaying patients' stories with respect and discretion.

According to the Medical Board of Australia's Code of Conduct,"*In professional life, doctors must display a standard of behaviour that warrants the trust and respect of the community. This includes observing and practising the principles of ethical conduct*" The code's Professional Boundaries section expands on this: "*Avoiding expressing your personal beliefs to your patients in ways that exploit their vulnerability or that are likely to cause them distress.*"[39]

- *"Lyme activists are not known to be scientific"*

  This is illogical; how is it possible that transmission is only occurring in people who do not have scientific aptitude?

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[39] Medical Board of Australia, *Good medicine practice: a code of conduct for doctors in Australia*, http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx

It's not – that's why I can easily give you some examples of scientifically minded patients. I refer you again to Karen Smith's site, which also has a copy of the Senate submission by patient Scott Chant, "*a self confessed science nerd"* with a degree in psychological science, who, in introducing himself, stated "*As a logical, scientifically minded proponent of evidence based medicine, I am an inherent sceptic of all things alternative, yet I have found myself being labelled as someone who believes in snake oil and pseudo science because I have tick-borne infections*."

Despite severe psychological symptoms, Scott's account of his illness is a professionally worded, appropriately referenced and objective account of his experiences.

In my own interactions with the Lyme community, I have found that the most common fields of employment are scientific. Park rangers are the most prevalent profession, due to the outdoors fieldwork involved. There's also at least one biologist.[40] The next most common profession I'm aware of is nursing. LDAA President Sharon Whiteman was previously employed as a critical care nurse, and there's at least one nurse running a support group. (I won't mention her name, as I'm not sure if her profession is public knowledge.)

- *"Using up to four weeks of antibiotics is the treatment recommended to eradicate Borrelia."*

I refer you back to the earlier information I provided regarding the IDSA guidelines, and their removal from the American National Guidelines Clearinghouse database.

- "*My patient...felt worse than when she started treatment".*

Yes, it happens. All of the LLMDs I am aware of educate patients regarding herxes, and they also warn that patients may feel worse in general; some American LLMDs compare the impact of treatment to chemotherapy. It's misleading to imply that this is evidence of an incorrect diagnosis.

- *"She was bright yellow because high-dose antibiotics were causing liver failure. I sent her straight to hospital in an attempt to save her liver and her life"*

Every LLMD I know routinely orders blood tests to monitor liver functionality, or asks the patients to arrange for their GPs to do so. These blood tests are carried out, at a minimum, monthly, but sometimes more frequently, depending on the individual's case.

- *"...where vulnerable patients are being scammed with expensive unaccredited tests, where unscientific and untruthful diagnoses are handed out, and where inappropriate and bogus treatments are endangering lives of already unwell people".*

This is a highly subjective statement. As is evidenced in more than 1000 submissions lodged by patients, carers and their treating practitioners, diagnosis of Lyme or Lyme-like illness is not "*untruthful*", and the

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[40] Maitland Mercury, Maitland woman Kazz Tokek wants her life back after Lyme disease battle, 29 Aug 2016, http://www.maitlandmercury.com.au/story/4126213/lyme-disease-survivor-desperate-for-work-after-health-battle-photos/

treatments are not “*inappropriate and bogus*”; in fact, they have significantly improved quality of life for many patients, as ACIIDS have been saying for years.. In the Sydney hearing, Dr Richard Schoeffel estimated a 70% recovery rate. (I am unsure of the reason that the remaining 30% don’t recover; possibly it’s due to the amount of damage inflicted on their body prior to diagnosis; an LDAA patient survey found that it takes patients an average of 10.75 years to be diagnosed.)

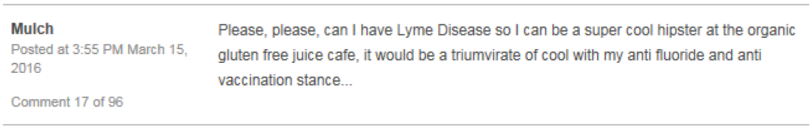
- *“Please note that this information is not an opinion, but has been written in consultation with some of Australia’s leading infectious disease physicians and pathologists”.*

It’s a pity - and an oddity - that these sources weren’t directly quoted.

- *“Let’s end the conspiracy and work together”*

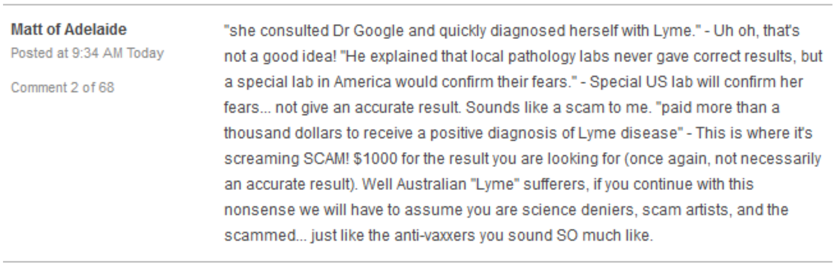
I don’t believe there is anything about this article that encourages “working together.”

The subsequent comments from readers reflect the emotional reaction that I believe was intended. These include comments from some who may not know better:



Mulch
Posted at 3:55 PM March 15, 2016
Comment 17 of 96

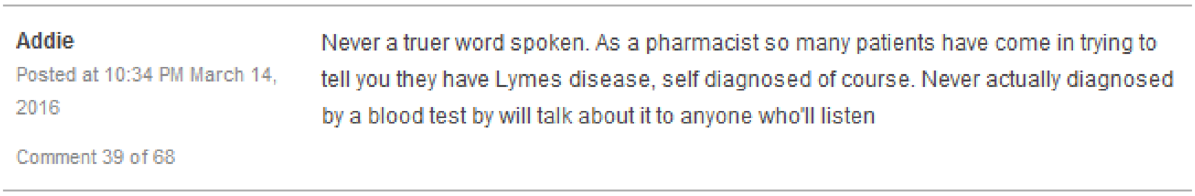
Please, please, can I have Lyme Disease so I can be a super cool hipster at the organic gluten free juice cafe, it would be a triumvirate of cool with my anti fluoride and anti vaccination stance...



Matt of Adelaide
Posted at 9:34 AM Today
Comment 2 of 68

"she consulted Dr Google and quickly diagnosed herself with Lyme." - Uh oh, that's not a good idea! "He explained that local pathology labs never gave correct results, but a special lab in America would confirm their fears." - Special US lab will confirm her fears... not give an accurate result. Sounds like a scam to me. "paid more than a thousand dollars to receive a positive diagnosis of Lyme disease" - This is where it's screaming SCAM! $1000 for the result you are looking for (once again, not necessarily an accurate result). Well Australian "Lyme" sufferers, if you continue with this nonsense we will have to assume you are science deniers, scam artists, and the scammed... just like the anti-vaxxers you sound SO much like.

..and those who definitely should:



Addie
Posted at 10:34 PM March 14, 2016
Comment 39 of 68

Never a truer word spoken. As a pharmacist so many patients have come in trying to tell you they have Lymes disease, self diagnosed of course. Never actually diagnosed by a blood test by will talk about it to anyone who'll listen

(When, may I ask, is it a requirement that patients present pharmacists with serology?)

I lodged a complaint with the HCCC regarding this article, primarily on the grounds of the what I perceived to be breaches of the Medical Board of Australia’s Code of Conduct, as earlier mentioned. The complaint (and a subsequent request for a review) were dismissed. Apparently Dr McKay’s conduct is completely acceptable.

I also lodged a complaint about Dr McKay’s article with the Australian Press Council. (I realise that they are not a government organisation; I’m only including reference to them here as it seems the most logical place to detail complaints.)

My complaint included reference to the following APC General Principles

*"*Accuracy & clarity – no reference to readily available scientific studies & patient case studies to the contrary of his view*

** Fairness and balance – patients are referred to in disrespectful manner. Author directly claims article is "information, not an opinion" because he has consulted experts, but experts aren't named or quoted*

**Avoidance of harm – tone of article could incite ridicule of vulnerable patients, some of whom experience psychological symptoms (one recently suicided after writing his Senate submission http://www.lymeaustralia.com/scott-chant-feb-2016/scott-chant-submission-for-senate-inquiry-into-lyme), & availability of comments section allows audience opportunity to ridicule"*

This complaint, too, was dismissed. The reasoning repeatedly referred to the fact that the article was "*an opinion piece*" and that "*such articles are entitled to express robust and, at times, provocative views."* I disputed this on the grounds that Dr McKay specifically wrote "*Please note that this information is not an opinion."* I didn't receive an answer to this for approximately six weeks, despite numerous emails and phone calls. During this time, I was able to determine that complaints about media reports that do not directly mention the complainant, cannot be disputed.

In the ARRL's submission, they stated "*"We do not accept that there is any more stigma associated with "Lyme-like illness" than there is to many other medical conditions from which many Australian patients already also suffer. "Stigma" may be in the mind of the beholder. Some patients may perceive that they are being stigmatised, but are probably not."*

I don't know on what grounds the ARRL believe they are in a position to make such an assumption, given that they are not patients themselves, but in light of the above complaints, I'd like to invite them to revisit their position.

Whatever the causes of the government's woefully inadequate response to date, they need to be identified, and rectified. Permanently.

Unfortunately, this is not the first time a government has shoved its head in the sand in relation to an infectious disease; Dr Jessica Bernstein has written an article[41] comparing the American government's wilful ignorance of the AIDS epidemic of the 1980s to the current situation with Lyme patients.

There are significant parallels between America and Australia regarding treatment of Lyme and Lyme-like illness. There is therefore somewhat of a precedent, and yet the government continues to act inappropriately, despite protests from patients, members of the healthcare profession, the media and (apparently) NSW Parks and Wildlife Services.

I believe the government is risking civil action and possible compensation claims from patients – the longer it continues to do so, the larger the claim, and the bigger impact on government funding for the greater community.

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[41] Bernstein, *From AIDS to Lyme – will we let history repeat itself?*, http://www.truth-out.org/news/item/21206-from-aids-to-lyme-will-we-let-history-repeat-itself

The government's ineffectual response to the Australian Lyme situation

Questionable input into the debate has become the norm

I believe the government's apparent apathy to the Australian Lyme patient community has contributed to the amount of questionable content being added to the public debate.

In the months after the RCPA released its Position Statement, Prof Graves again stirred up controversy in his appearance on the Sunday Night program on which he was identified as a CACLD member.[42]

Prof Graves speculated that overseas labs were returning positive results for Borrelia in Australian patients because *"I think their philosophy is you pay us money, we'll give you the result you want*", completely overlooking the fact that while some patients want a positive result, many people, including the asymptomatic relatives of patients, do not (who would *want* to be in the situation Lyme patients are in?!)

The possibility of a defamation case by the labs in question appears to have been disregarded.

Not only that, but [name of American lab redacted], makes it very clear on both test results (as copied earlier in this document) and via presentations delivered at the ILADS conferences, that a Lyme diagnosis is primarily a clinical one. So why they would bother 'selling' results is a mystery.

Prof Graves follows up that statement by saying that laboratories "*are a business, let's put it that way*". This quote is particularly surprising, given that Prof Graves is a spokesman for the RCPA. Australian laboratories are businesses, too, and I've paid for tests for all kinds of things, too – should I assume the results returned to me were based on what the pathologists thought I wanted to hear?

Another example of questionable input is the latest offering from Dr Brad McKay. Recently an article[43] was published regarding Yolanda Hadid's assertion that Lyme is comparable to HIV. The article reported "*Sydney GP Dr Brad McKay said Ms Hadid's comparison was a long bow, with the two not on par. "If HIV isn't treated, people die. If Lyme Disease isn't treated, then people can feel unwell for a very long time," McKay said."*

This fails to address the reason for Yolanda's comparison. Yolanda makes no mention (in the article, at least) of mortality rates. Instead, her comments are reported as follows: *""We all pull together so beautifully for HIV," Hadid said. "Lyme is three times more prevalent right now, it's a world-wide epidemic, the first case was diagnosed in 1972… yet we haven't done anything about it."*

Yolanda is talking – understandably – about the lack of action by her own government in relation to Lyme disease. She is not the first to make this comparison. Dr Marc Conant was one of the first to identify AIDS in 1981, and is now interested in Lyme disease. In 2014, he drew parallels between chronic Lyme and AIDS, stating "*Both diseases have introduced an unexpected paradigm into medicine. In the early '80s, the medical establishment thought they knew everything about infectious disease, so when AIDS came along, researchers insisted that it could not be an infection. Instead, they assumed that the symptoms must be due to environmental factors such as sexual practices or recreational drugs*."[44]

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[42] Sunday Night, *Australians flock to overseas Lyme treatment,* 24 Nov, 2014, https://au.news.yahoo.com/sunday-night/a/25588947/australians-flock-to-overseas-lyme-disease-treatment/#page1

[43] Molloy, *Mother of Gigi and Bella Hadid says Lyme disease is comparable to HIV*, 8 Nov 2016, http://www.news.com.au/entertainment/celebrity-life/mother-of-gigi-and-bella-hadid-says-lyme-disease-is-comparable-to-hiv/news-story/c5ec2d8135dc7b292c1d866103a67be1

[44] Bernstein, *From AIDS to Lyme – will we let history repeat itself?*, http://www.truth-out.org/news/item/21206-from-aids-to-lyme-will-we-let-history-repeat-itself

Likewise, Australia's Dr Richard Schloeffel has made similar comparisons. When speaking at the Brisbane inquiry hearing, Dr Schloeffel recounted his experiences as a young doctor during the 1980s, stating "*There was the same sort of thought process among the medical profession, that some people are better than others and there was no emergency." In drawing comparison to Lyme, he says "The array of symptoms is enormous, which makes it different to AIDS, but the problem is the same. If you deny the illness is there but you have all these people sick, then what is wrong with them? If you say to them, 'Yes, you are sick. There's nothing you can do,' or, 'You're just putting it on,' that is not real medicine. That is denialism*" Dr Schloeffel's testimony was considered so powerful it was included in the Senate's Interim Report.

The fact that Dr McKay's interpretation of Yolanda's comments was so out of context, indicates that appropriate research was not conducted prior to his response.

I am also concerned that some submissions authored by professional organisations have not been completed with the degree of diligence I had hoped for. For example, the Australian College of Dermatology (submission 455) included a section titled "*Evidence of Lyme Disease in Australia."* This made no mention of the evidence I referred to earlier, of "*Six cases of ECM (Erythema chornicum migrans) have been diagnosed by Hunter Valley dermatologists over the last 12 months, which indicates that the aetiological agent is well established in the area, and more cases of Lyme arthritis may be expected."*

Instead, the college stated that *"For the purposes of this report, an internet survey was carried out to all Australian dermatologists, whereby they were asked if they had ever seen, or were aware of, a case of confirmed Lyme disease in their practicing lifetime.*

This included dermatologists who have worked for many years in coastal regions, and who have seen many cases of tick-bites and other insect bites. The responses were all negative."

I have personally only reviewed about 0.02% of all published submissions, but noted that two of these included diagnoses by dermatologist. Submission 35 states that "*…while visiting my local dermatologist checking my skin problems, he noted my walking and breathing problems and then made a suggestion - you may have LYME DISEASE. Thanks to him, I have since had tests done and been to see two Lyme Literate Medical Doctors, who have said I have probable Neuroborelliosis."*

Submission 78 states that*: "He sent me to a dermatologist in Fremantle. I was a bit stunned when I started to tell the specialist my story and after a very short time he cut me off and said… "You have Lyme disease." As I recall, this specialist had recently spent three months in Austria and saw a lot of it there. He also interestingly stated to me that Lyme disease has always been in Western Australia, and that the old stockmen knew that getting tick bites would make you sick. He did also say that he would never stand up and declare this in Public though, I didn't understand why, and never discussed it."*

Finally, the suggestion by members of the scientific and medical community that the use of the term 'Lyme' is causing stigma among their colleagues also strikes me as inappropriate.

it is often implied that patients do not have an objective mindset, unlike the scientific community, but to me, the oft-repeated request that the word 'Lyme' be removed from the debate proves that this is not true. That scientific professionals are so easily impacted by negative connotations, and believe that impact to be sufficiently acceptable that they would openly and repeatedly share this information, is alarming.

I believe it is reasonable to expect such professionals to have the mental agility and objectivity to say "*We don't know what this condition is, but we need to find out as a matter of urgency. There is no room in this discussion for stigmas and prejudice, lives are at stake. It's all hands on deck; leave your personal and* *professional issues at the door. The opportunity to be part of something that can improve lives so significantly is a privilege and an honour – let's treat it as such."*

In my previous role as a Business Analyst, I was expected to have the mental stamina and emotional resilience to approach issues with an open mind and solution-focussed approach, regardless of my preconceived ideas. I was able to achieve this, despite not having a university degree or the level of responsibility that comes with the roles these scientific professionals have chosen. Not to mention the pay packet. If I was to have suggested that this was not a reasonable expectation, my manager would have been staggered.

I believe that in large part, the request for the word 'Lyme' to be removed, is so that the credibility/egos/reputations of those who decided many years ago that there is no Lyme in Australia, will not be damaged. Again, in my role, sometimes my initial recommendation was incorrect, in which case I corrected it as soon as I could. This was possible because my ego did not play a part in my professional interactions; I treated it with the objectivity required. The issue of scientists' egos and reputations should not be taking precedent over patients' lives.

Lack of public awareness/commitment to disease

Despite evidence of Borrelia in Australia dating back to the 1950s, and cases of human infection reported since the 1980s, the government has failed to provide the community with any valuable public education or indeed direction, and are still sitting on the fence.

We'll never know how many patients have been affected by a Lyme-like illness, as so few doctors will even consider it as a diagnosis. Not that they are required to notify authorities about such a diagnosis anyway.

We'll never know how many people have died (through the illness itself, or via suicide/euthanasia), and whether any of those deaths could have been prevented had the government validated the illness, so that it is considered 'legitimate'.

An example of what I consider a 'legitimate' disease is cancer – patients receive unanimous public sympathy (to the point that people like Belle Gibson will even fake it for attention[45]), and many patients, myself included, have had doctors use it as a benchmark to imply we are over-reacting; "*Some people have cancer, you know*!"

This emotional response to cancer is undoubtedly influenced by how many people's lives have been touched by the disease, granted, but I believe people have extended that emotional prioritisation to an intellectual one. How else can you explain Samuel Johnson blithely stating "*Cancer is the last true riddle of our time (not of our doing)"*?![46]

I fervently hope that my comments are not interpreted as disrespect to cancer patients, or an attempt to minimise the suffering endured by themselves and their family; my own father is in remission from prostate cancer – but I believe there is room in our community to support other illnesses, too, particularly ones that can cause many years of excruciating pain and debilitation prior to diagnosis, involve treatment comparable in discomfort to chemotherapy, and result in depression and suicidal ideation not just as a consequence, but as a symptom.

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[45] Donelly, *Analysis: Cancer scammer Belle Gibson must be held accountable*, 6 May 2016, http://www.smh.com.au/national/analysis-cancer-scammer-belle-gibson-must-be-held-accountable-20160505-gong89.html

[46] AAP, *Samuel Johnson retires from acting*, 26 Feb 2016, http://www.news.com.au/national/breaking-news/samuel-johnson-retires-from-acting/news-story/6238db4bf2b1644937612defae36fd33

Borrelia is thought to be primarily transmitted via tick bite; given the amount of bushland in Australia, and our outdoorsy lifestyle, I don't see how the government can justify its failure to fully identify a very significant risk, and respond appropriately.

In my opinion, the majority of the media have not demonstrated a commitment to dealing the full story when it comes to the Australian Lyme situation. Despite the senators deftly identifying significant issues within the responses of public servants and other authorities, very little of this has been reported. For example, although SBS World News[47] reported that the content of the Sydney hearing was *"explosive"*, they didn't screen any explosive content, such as the interaction between Senator Reynolds and Dr Lum that I previously referred to. Instead, we saw Prof Graves repeating a very similar opinion to what was aired on SBS' Insight program[48] just one week previously.

When Dr Gannon first made the comments regarding the inquiry that I find so disturbing, I approached numerous media outlets for help, including some who had previously used material from patients' perspectives. Not one replied. In fact, I was disappointed and hurt when one of those outlets, Channel 10's The Project, concluded their next segment[49] about Lyme with Waleed Aly stating "*Doctors are being really sincere about this*."

Generally speaking, people listen to the government when it comes to health priorities, and the government is quite simply letting us down. Which brings me to….

Reluctance of the general community to support the Lyme cause

Despite the propensity of Australians to take our politicians down a peg or two, since being diagnosed with Lyme, I've learned that the government has an almost impenetrable underlying degree of influence, that has made getting practical support for the Lyme cause from my friends and family literally impossible.

Immediately after diagnosis, I felt a responsibility to get politically involved, and soon took on a role as National Coordinator for the inaugural Worldwide Lyme Protest (WWLP). With the help of the Lyme community, Ryan and I created these videos, in order to garner support for the event:

Overview video

Detailed video – "I am"

Detailed video – "I've lost"

Detailed video – "I want"

We shared these videos, and a link to the 'Worldwide Lyme Project – Australia' Facebook page, in the hope of inspiring the support of our friends and family. Given that the closest protest event to us was to be held

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[47] SBS World News, Patients say Lyme disease on increase, despite official denial of its existence in Australia, 2 Nov 2016, http://www.sbs.com.au/news/article/2016/11/03/patients-say-lyme-disease-increase-despite-official-denial-its-existence

[48] SBS Insight, '*Tick Sick*', 25 Oct 2016, http://www.sbs.com.au/news/insight/tvepisode/tick-sick

[49] The Project, '*Lyme Limbo*' 14 Jul 2016. The segment is available on the Facebook pages of both The Project and the LDAA.

outside NSW Health headquarters on a Friday afternoon, we understood that many people wouldn't be able to attend due to work commitments, and offered alternative methods of support, such as the below:

Janice Foster shared GLOBAL Lyme Project - Australia's photo
April 20, 2013 ·

Peeps looking for an esay way to support the protest - here it is!

GLOBAL Lyme Project - Australia
April 20, 2013 ·

Why not host a Lyme awareness morning/afternoon tea during the protest period? We've made it easy for you!

You can download a poster/invitation advertising your tea here:

http://worldwidelymeprotestaustralia.weebly.com/posters.html

The LDAA's Lyme brochure is available here:

http://www.lymedisease.org.au/.../2013/04/LDAA-Flyer-DOWNLOAD...

Although the videos did evoke an emotional response with friends reporting "tears", only one colleague showed up to the protest ("*because my family like supporting the little guys*"). Ryan's parents also attended at his urging.

No one, to my knowledge, took the option of hosting a morning tea.

By the time the 2014 WWLP event rolled around, I'd been exposed to so much distress (see 'Patient Stories'), that I was more dogged in asking for people's involvement.

Janice Foster shared GLOBAL Lyme Project - Australia's photo.
May 15, 2014 ·

Sorry for re-posting this, but had to delete the original as someone wanted their photo blanked out on the pic of last year's banner.

Anywayz, there's still time to get involved - Jenny is accepting pics until 9am tomoz! If you like, you can just tag me in a photo of you, and I'll make sure Jenny gets it.

GLOBAL Lyme Project - Australia
May 15, 2014 ·

Do you support the Sydney protest at Nepean Hospital, but are unable to attend? Australians everywhere are invited to email a photograph of themselves to Jenny ...

See More

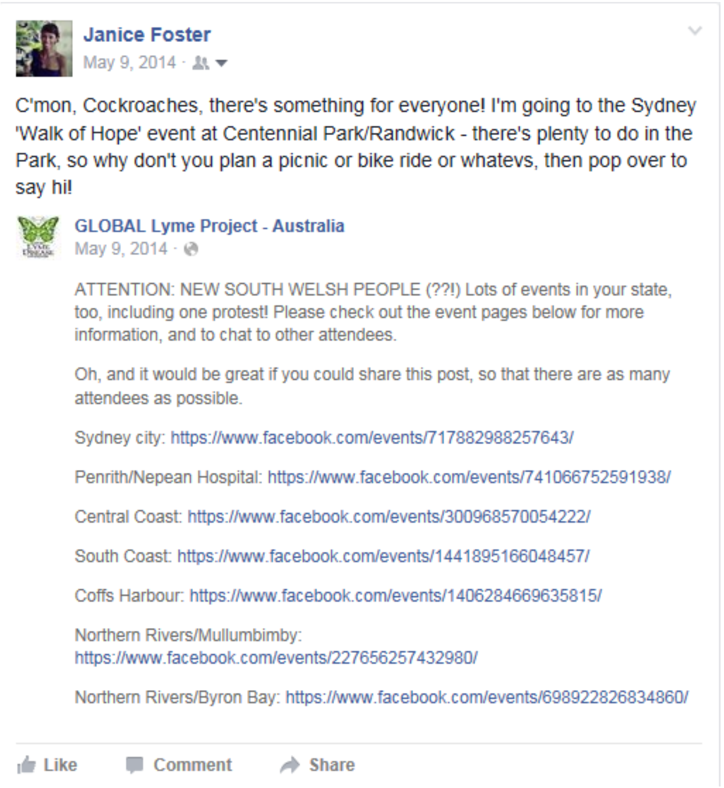
Janice Foster
May 15, 2014 ·

Tweet up a storm!

Janice Foster
May 13, 2014 ·

Anyone interested in hanging out in Centennial Park on Satdee, for Lyme disease awareness? The weather is forecast as sunny and 23 degrees - might as well make hte most of the good weather whilst it lasts!

MAY 17
NSW: Sydney: Randwick - "Worldwide Ly...
Sat 12:30 PM · Centennial Park · Sydney, NSW, Aus...
6 people interested · 26 people going



Janice Foster
May 9, 2014 ·

C'mon, Cockroaches, there's something for everyone! I'm going to the Sydney 'Walk of Hope' event at Centennial Park/Randwick - there's plenty to do in the Park, so why don't you plan a picnic or bike ride or whatevs, then pop over to say hi!

GLOBAL Lyme Project - Australia
May 9, 2014 ·

ATTENTION: NEW SOUTH WELSH PEOPLE (??!) Lots of events in your state, too, including one protest! Please check out the event pages below for more information, and to chat to other attendees.

Oh, and it would be great if you could share this post, so that there are as many attendees as possible.

Sydney city: https://www.facebook.com/events/717882988257643/

Penrith/Nepean Hospital: https://www.facebook.com/events/741066752591938/

Central Coast: https://www.facebook.com/events/300968570054222/

South Coast: https://www.facebook.com/events/1441895166048457/

Coffs Harbour: https://www.facebook.com/events/1406284669635815/

Northern Rivers/Mullumbimby:
https://www.facebook.com/events/227656257432980/

Northern Rivers/Byron Bay: https://www.facebook.com/events/698922826834860/

To my knowledge, not one family member, and very few friends from the healthy community got involved in any way – not even to contact me to apologise that they couldn't attend, or wish me well prior to the event.

It's noteworthy that unlike the Sydney event of 2013, this wasn't a political event that might make attendees feel like they had to read up on the issue; it was a simple gathering at Centennial Park, perfect for even those with young kids!

It would be easy to conclude that my friends and family either didn't care, or had Lyme overload (although I have always been very careful to limit my Lyme-related Facebook posts, as are many patients).

But they do care – friends often put motivational posts on my Facebook page, and, as per below screenshots, immediately mobilised over a single day to win me a free lymphatic drainage massage from my therapist.

Janice Foster
November 1, 2014

Morning peeps! If you have a second, could you please like page, and then tag me in the comments of the below post has made?

The person who brings the most new 'likers' to n's page gets a free massage, and I am running low on $$!

Thanks, and have a great weekend (and OMG, if you are in Syd or Central Coast, watch out for the sun - it's already bitey!)

October 31, 2014

WE ARE RUNNING THIS COMPETITION AGAIN Due to Facebook not showing this fairly

Let's start a relaxation revolution!

Get your friends to like

Janice Foster
November 1, 2014

THANK YOU to everyone who helped me out by liking the page. Because of you, I WON THE FREE MASSAGE!

V v happy, thank you so much! It's been a rough 48 hours - Lymies don't cope well in the heat the best of times, and I had a 4.5hr round trip/ordeal to Sydney yesterday on public transport, spent over $1000 on medical treatment, had my keys run over in a carpark, dropped and broke a potato salad container in Woolies AND my dog peed it's bed.

So...a very nice end to a yucky coupla days; not only winning a damn good massage for free, but also knowing I won it coz my friends cared enough to do this for me. Thanks again xxx

They also care about the Lyme community – some friends joined the online Red Shoe Day event, in which people posted photos of themselves wearing red shoes in memory of Australian Lyme patient Theda Myint, who had 'euthanised' herself, as her mum puts it, on that day the previous year.

Janice Foster Red Shoe Day:
https://www.facebook.com/events/253764474820850/?ref_newsfeed_story_type=regular

JUL
25
Red Shoe Day - Worldwide Online
Jul 25, 2014 - Jul 27, 2014 · Worldwide: Pl...
45 people interested · 941 people going

One friend of Ryan's even got in contact with me to ask how she could further help, resulting in us co-hosting a 4WD fundraiser held for a young patient living in a care facility, in 2015.

So, if people care, why didn't they get involved with the WWLP? My guess is that they didn't want to associate their names with the activism side of things because the government's influence is wide, and if the government don't believe in locally acquired Lyme (or extensive treatment for Lyme acquired overseas), then there's a real possibility it's invalid, and no one wants to risk being made to look a gullible fool.

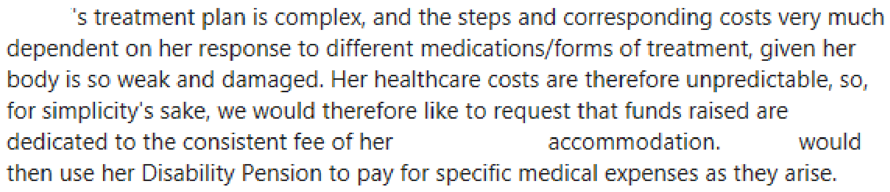
<u>Possible reluctance of charities and businesses to support the Lyme cause</u>

While planning the 4WD fundraiser, I became aware that under the NSW Charitable Fundraising Act I needed to engage a not-for-profit organisation with an authority to fundraise, to ensure that the event met legal requirements.

Given the formidable workload already facing the LDAA and KMF, I sought the advice of the NSW Office of Liquor, Gaming and Racing for an alternative source of support. They suggested I contact the [charity name redacted] so I immediately emailed the [charity name redacted], briefly outlining the patient's situation, asking if they would consider helping, and if so, what they require of me.

[charity name redacted] sent me a detailed reply, covering the information they needed, including "documents to support your request."

I immediately got to work on my application. Although the money was originally to be raised for ongoing Lyme treatment, I realised that the [charity name redacted] might be uncomfortable with being seen to support complex treatment of a controversial illness, so I tried to make things as easy as possible for them, by stating



's treatment plan is complex, and the steps and corresponding costs very much dependent on her response to different medications/forms of treatment, given her body is so weak and damaged. Her healthcare costs are therefore unpredictable, so, for simplicity's sake, we would therefore like to request that funds raised are dedicated to the consistent fee of her accommodation. would then use her Disability Pension to pay for specific medical expenses as they arise.

I enclosed five supporting documents:

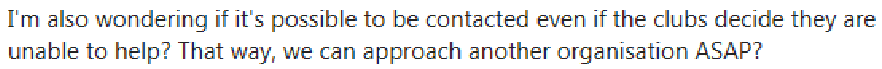
- A letter dated in 2013 from the patient's LLMD to the Clinical Director of Operations at the Children's Aged and Community Health department, outlining the nature of the patient's illness and incapacitation, and the need for "*total care*", as at the time the patient was living in the general community unsupervised
- A letter from Family and Community Services, also dated 2013, denying the patient in-home support as "*the (high) level of assistance cannot be provided by the ACP and HNP*"
- A second letter requesting "*total care*" for the patient, this time from another doctor, as the patient had moved away from the LLMD's location

- A letter from the Department of Social Services dated 2014, confirming that the patient was eligible for residential care

- A statement of daily fees from the residential facility in which the patient was eventually residing, proving the costs involved

This seemed to me a reasonable and thorough submission – I had avoided possible controversy for the [charity name redacted]] by stating that funds would go towards residential care, provided written statements from two doctors requesting the said residential care, and two letters from the government agreeing that residential care was required and proved the care was indeed taking place.

Being aware that if the [charity name redacted] decide not to fulfil a request, they don't notify the submitter, I finished my email by writing:



I'm also wondering if it's possible to be contacted even if the clubs decide they are unable to help? That way, we can approach another organisation ASAP?

I never heard from the [charity name redacted] again.

Of course, I don't know for sure that they were scared off by the Lyme diagnosis, but I can't imagine why else support would be denied an obviously extremely ill patient, nor why someone couldn't even take five minutes to notify me as I'd requested, allowing me maximum opportunity to seek help elsewhere.

Around the same time as the [charity name redacted] request, I contacted the [name of local attraction redacted] regarding [identifying details of attraction's promotional tool redacted]. The [name of attraction's promotional tool redacted] is often used to raise awareness for causes, by prominently displaying awareness ribbons. I hoped [name of promotional tool] could be used to promote Lyme awareness month by featuring a Lyme ribbon.

The [name of local attraction redacted]'s Marketing Assistant advised me that a letter from the LDAA would be required to formalise the request, including acknowledgement that the LDAA would pay for the [details of cost of promotion redacted].

As an LDAA volunteer, I worked with the President to finalise the request letter and the design. I even provided a mock up of how this might look.

The letter was acknowledged by the Marketing Assistant on 25 October 2014, with the commitment that "*Your proposal will be brought to the attention of our management team for approval at the next meeting. Once I am aware of the outcome I will be in contact to notify you".*

I never received notification of an outcome. I basically got the run around. In November the excuse was "*Our manager is away at the moment*". In December "*the majority of our management team are out of the office so it may not be until the new year that the proposal is assessed:"*

By March 2015 we still hadn't received an answer, and requested an update. I can't find the remaining emails of the saga, but basically it became clear that the [name of local attraction redacted] was continuing to drag its feet, so with the awareness month looming, we had to cut our losses and withdraw our application in order to focus our time on organisations that would take us seriously.

These two rejections had a serious emotional impact on me; patients had been banging their heads against a wall trying to get government assistance, and now organisations within the general community were responding with similar indifference. There's only so many brick walls you can hit without shattering, and part of me shattered.

Another example I can think of dates back to early 2013. I contacted my local newspaper, the [newspaper name redacted] via their online form to introduce myself as a National Coordinator for the WWLP. I offered to be interviewed, and explained I'd gotten the agreement of other local patients to participate in a photo opportunity if required. I also tied in the fact that one of the earliest reported cases of Lyme in Australia, was local.

I received no response, and in the years that have since passed, I have continually seen the [newspaper name redacted] publish articles about sick residents, residents involved in charities, and more inane stuff about people who have been visiting the same local caravan park for 50 years.

I don't understand why people don't care about us enough to even look at the Lyme situation with an open mind. It makes me feel very small, very worthless, very unheard, and very sad.   What hope have we, if neither the government nor the general community are responsive?

<u>Opportunities for manipulation of patients by others</u>

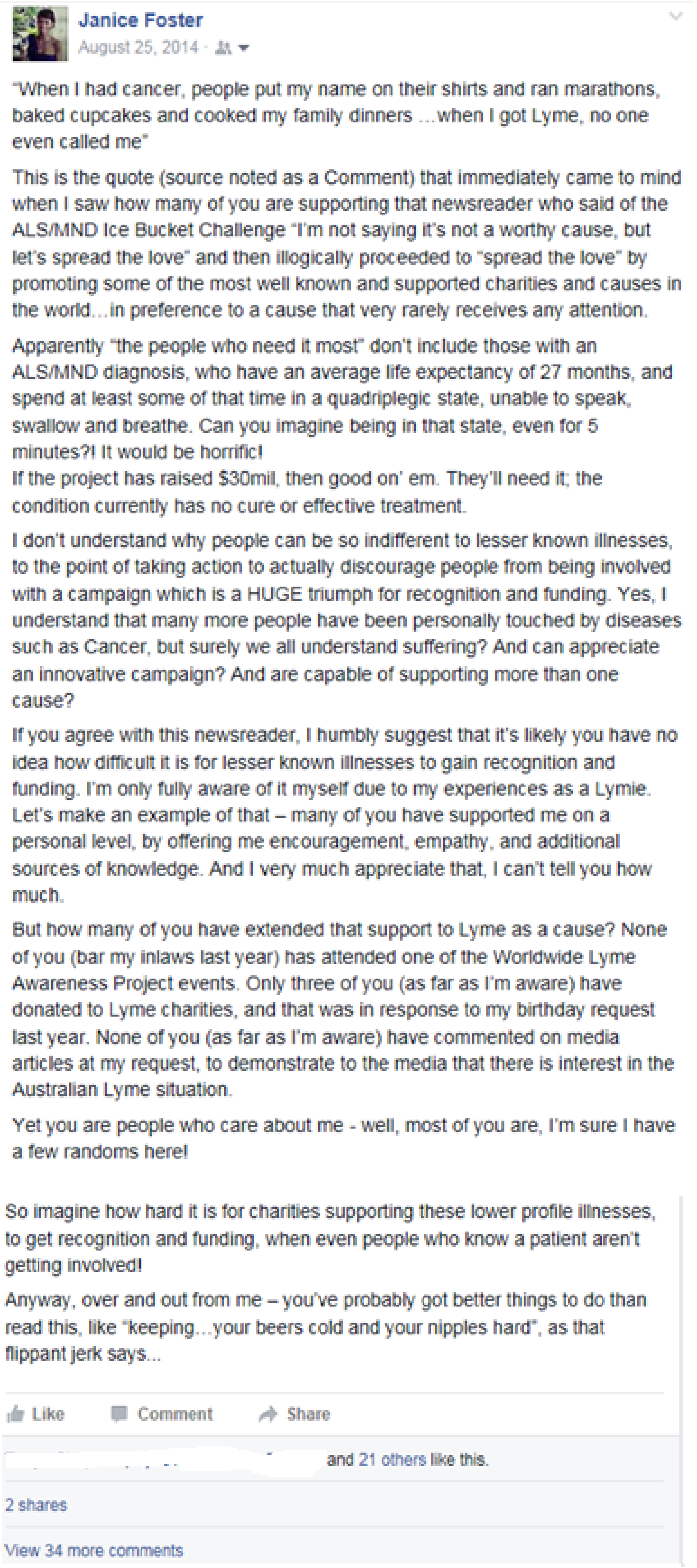
I thought long and hard about including this example, for fear it would taint my very genuine and heartfelt submission with a 'Jerry Springer' style flavour.

However, I eventually decided it should be included, as it illustrates an example of an experience many patients have had; the withdrawal of support for our cause by a friend or loved one as an act of revenge or malice.

I do have some worthwhile conclusions to draw from these experiences that I'd like to share; please just bear with me through the melodramatic bit, then I'll be better able to make my points with context.

As you can see from the below screenshots, I've captured a rather controversial post I made on my Facebook page, expressing frustration about the public backlash for the ALS Ice Bucket challenge. A friend felt I was using this as a vehicle to shame people for not actively supporting the Lyme cause. I wasn't; I am a very forthright person and say either exactly what I mean, or nothing at all – I think it's cowardly to hide behind agendas, and to use patients of fatal illnesses like ALS for these purposes would be both trivialising and disrespectful.

Anyway, Ryan saw the friend's reply first, and hastened to answer it before I saw it and felt upset. The friend replied with an expression of support, and a thought of one day helping with the Lyme issue once she'd finished her degree.



Janice Foster
August 25, 2014 ·

"When I had cancer, people put my name on their shirts and ran marathons, baked cupcakes and cooked my family dinners …when I got Lyme, no one even called me"

This is the quote (source noted as a Comment) that immediately came to mind when I saw how many of you are supporting that newsreader who said of the ALS/MND Ice Bucket Challenge "I'm not saying it's not a worthy cause, but let's spread the love" and then illogically proceeded to "spread the love" by promoting some of the most well known and supported charities and causes in the world…in preference to a cause that very rarely receives any attention.

Apparently "the people who need it most" don't include those with an ALS/MND diagnosis, who have an average life expectancy of 27 months, and spend at least some of that time in a quadriplegic state, unable to speak, swallow and breathe. Can you imagine being in that state, even for 5 minutes?! It would be horrific!
If the project has raised $30mil, then good on' em. They'll need it; the condition currently has no cure or effective treatment.

I don't understand why people can be so indifferent to lesser known illnesses, to the point of taking action to actually discourage people from being involved with a campaign which is a HUGE triumph for recognition and funding. Yes, I understand that many more people have been personally touched by diseases such as Cancer, but surely we all understand suffering? And can appreciate an innovative campaign? And are capable of supporting more than one cause?

If you agree with this newsreader, I humbly suggest that it's likely you have no idea how difficult it is for lesser known illnesses to gain recognition and funding. I'm only fully aware of it myself due to my experiences as a Lymie. Let's make an example of that – many of you have supported me on a personal level, by offering me encouragement, empathy, and additional sources of knowledge. And I very much appreciate that, I can't tell you how much.

But how many of you have extended that support to Lyme as a cause? None of you (bar my inlaws last year) has attended one of the Worldwide Lyme Awareness Project events. Only three of you (as far as I'm aware) have donated to Lyme charities, and that was in response to my birthday request last year. None of you (as far as I'm aware) have commented on media articles at my request, to demonstrate to the media that there is interest in the Australian Lyme situation.

Yet you are people who care about me - well, most of you are, I'm sure I have a few randoms here!

So imagine how hard it is for charities supporting these lower profile illnesses, to get recognition and funding, when even people who know a patient aren't getting involved!

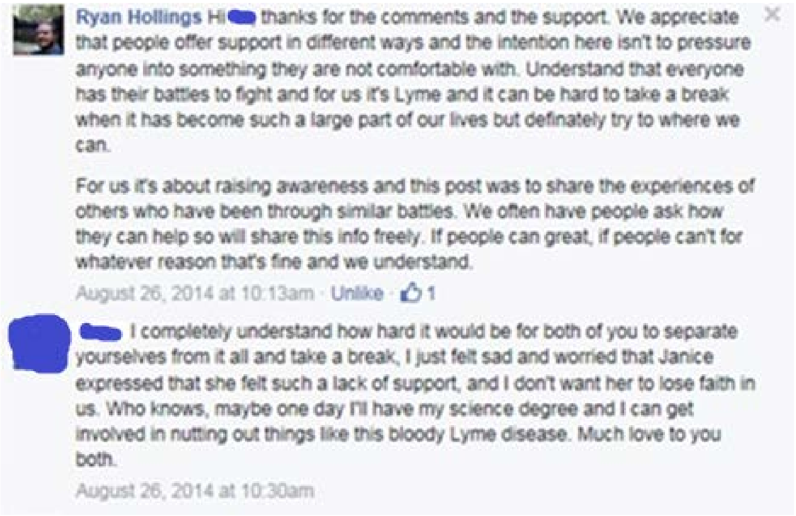
Anyway, over and out from me – you've probably got better things to do than read this, like "keeping…your beers cold and your nipples hard", as that flippant jerk says...

[redacted] and 21 others like this.

2 shares

View 34 more comments

[redacted] [redacted] Janice, as someone who was chronically ill for a very large part of my youth, and who suffered physically and mentally because of it, I know what it's like to be so sick you can't participate in life the way you would if you were well. I worked hard to be well again and now I don't look back. I still remember how it felt to be that ill and in that much pain though, and I get tastes of it again every time I go through the common things most of us experience at one time or another when we get really sick or we have surgery or hurt something really badly. I've extended gestures of compassion and empathy to you before so I'm sure you already know I've felt for you over the time you've shared what you've been going through. I've shared at least one post you've shared about Lyme disease I'm sure, so it makes me sad that you feel the way you do. A person's ability to feel compassion isn't measured by the dollars they give or the posts they share, and no one should ever be shamed for not donating money to something. -A person's right to anonymity is the first thing that should be respected when asking for donations. Most of us go through a living nightmare at one time or another. Some of us share our journey, some of us hide it away. I understand that awareness about Lyme is important in terms of funding for research and treatment, and I'm sure that most would agree with me on that. Lots of us are fighting causes, some just just as hopeless as yours may seem at times. We can't fight them all but I'm sure we're all cheering for each other. Maybe it's time to have a break from the whole Lyme thing for a while. It's a frustrating plight for you, don't let it wear you down and make you doubt our support. You might end up getting bitter and that's not good for your gallbladder. Or your face (in terms of wrinkles). Keep rallying but remember to have time off. Getting well is more important than anything I reckon. Feel the love, my friend. Peace. xo



Ryan Hollings Hi [redacted] thanks for the comments and the support. We appreciate that people offer support in different ways and the intention here isn't to pressure anyone into something they are not comfortable with. Understand that everyone has their battles to fight and for us it's Lyme and it can be hard to take a break when it has become such a large part of our lives but definately try to where we can.

For us it's about raising awareness and this post was to share the experiences of others who have been through similar battles. We often have people ask how they can help so will share this info freely. If people can great, if people can't for whatever reason that's fine and we understand.

August 26, 2014 at 10:13am · Unlike · 👍 1

[redacted] [redacted] I completely understand how hard it would be for both of you to separate yourselves from it all and take a break, I just felt sad and worried that Janice expressed that she felt such a lack of support, and I don't want her to lose faith in us. Who knows, maybe one day I'll have my science degree and I can get involved in nutting out things like this bloody Lyme disease. Much love to you both.

August 26, 2014 at 10:30am

Once I saw her responses, I wrote a lengthy explanation clarifying my motives.

Over the next few days, we continued to post about our differences of opinion, in what I believe was a respectful manner. (I haven't included the entire thread, as it's very long and includes numerous comments by other friends, including the general support of a cancer survivor, that aren't relevant to this particular example). We both stuck to our guns, and she used smiley emoticons, presumably to take the heat out of the conversation.

A fellow patient took offence at her comments and found the use of the emoticons jarring, calling her a "*smiling assassin*". I told the patient that the friend was actually "*lovely*", in fact I'd had somewhat of a *"girlcrush*" on her, and that this was our first disagreement which I was sure we'd sort out.

The friend sent me a message saying I was a mean bully, and un-friended me. Presumably feeling hurt and a little upset that none of my commenters (patients or otherwise) had supported her position, she vented on her profile page about "*Lymies*", including the below comments that completely contradict the heartfelt support and the possibility of future practical support she'd offered just 48 hours earlier, despite no new evidence about the presence of Lyme in Australia, or lack thereof, being introduced during that period.

[redacted] Whats a Lymie?
August 28 at 11:38am

[redacted] Lymie is someone who suffers from Lyme Disease which doesn't exist in Australia (according to the experts).
August 28 at 11:51am

[redacted] I want to see the party Damn it! !
August 28 at 12:08pm

[redacted] Which means that the 'Lymie' culture here in Australia is absolute f[redacted]ing anarchy, and we have countless, unsupervised 'Lymies', with absolutely no medical knowledge whatsoever, self-diagnosing, self-prescribing, and crying 'Lyme' every time they fart or behave badly. It seems quite easy to be diagnosed with Lyme. You just send some of your blood to America along with $500 and 'viola', you're a Lymie.
August 28 at 12:08pm

Again, I am embarrassed to include such melodrama in my submission. I am glad to say it's the only instance of this kind of attack on the Lyme community 'inspired' by me that I'm aware of. But this kind of thing is not an isolated incident. I have spoken to many patients who have shared their distress and feelings of betrayal at friends or family turning on their cause in spite – I remember, for example, after another patient had an argument with her sister unrelated to her health, her brother-in-law started tweeting a well-known Australian scientist for his opinion on Lyme, and the tone of his tweets deteriorated from there.

I was made aware of this when the patient posted on one of the Lyme forums in tears, apologising because she felt somehow responsible for what she considered an attack that would impact us all. The Lyme community of course comforted her, and those with Twitter accounts began challenging the brother-in-law, who subsequently deleted these tweets.

The reason I am raising these examples, is to demonstrate that humans are emotional, messy beings. They don't always act rationally or with compassion towards those who are vulnerable. With that in mind:

- There are many Lyme patients who have family or friends who don't support the Lyme cause or their diagnosis. Just because they have or had a close relationship to these patients, doesn't mean their opinions are based on familiarity with the patients' ailments (or alleged 'lack of'), subsequent diagnosis and treatment, or a commitment to getting to the truth of the issue.

- Our government has a responsibility to care for the vulnerable, and a moral obligation to lead by example.

  The failure of the government to take the lead, or in fact provide any form of decisive ongoing commitment in relation to Lyme without significant pressure, creates the impression that the complaints of patients are not worthy of attention, nor, more importantly, respect.

> Where the government doesn't lead, people can't follow; hence, in my opinion, the persistent disregard for patients amongst the general medical community that results in doctors feeling so secure in their position that they have been known to openly mock patients, and respond in a highly emotional manner that should not be tolerated in a profession requiring members to act with compassion and objectivity.
>
> This behaviour from government officials and the medical community then forms an impression on the general public, who in some cases may use this as justification to ridicule patients, and in others, to use their support in a power play; as a bargaining tool or source of punishment when patients behave in a way not to their liking, as illustrated above.
>
> Patients are commonly already struggling with psychological symptoms, and to have the feeling that there is no safe place in our society, where we can expect the basic rights of being believed, treated with appropriate medical attention and provided with emotional support in our time of need, is devastating.
>
> Whether it has contributed to the suicide of Lyme patients, I can't say, but I'm sure we can all agree that it is certainly very damaging.
>
> Basically, what I'm trying to say is that often people will treat others badly unless they have reason not to – that's why we have laws, and that's why corporations these days are exhorting their company 'values', right?
>
> In the case of vulnerable Lyme patients, the government's indifference is not giving people a reason not to treat us badly – I believe it's a reasonable argument that the reverse is happening.
>
> Our public service has failed to serve the public, down to a community level.

My life today (as at March 2016)

On a great day, I can mow the lawn, do the grocery shopping, clean the house, listen to music or read a library book I've never read before. I come up with ideas, proactively engage people, and can express myself articulately.

I usually cook up huge batches of 'Janice friendly' meals, to use on the occasions I'm too fatigued to cook, which I stash in a freezer we've bought specifically for that purpose.

On an average day, I only have the attention span to read books I've read before, and am proud of any amount of cleaning up after myself that I can manage. I can respond to the demands of interactions with people with a minimum of stress, but sometimes stumble on pronunciation or simply can't find the word I'm looking for – it's a bit like I'm tipsy.

I can move around freely, but I'll only walk around if I have to. Often, my spatial awareness is a bit dodgy and I'll bang my shoulder into the side of a doorway, or consciously concentrate in order to safely walk down a set of stairs.

Sometimes I'll randomly get dizzy very suddenly, and need to sit down immediately.

I'm a bit sensitive to noise, and will ask Ryan to juice my celery for me, while I wait at the other end of the house.

On a bad day, I sleep for up to 18 hours. I try and isolate myself, because even the movements of others (including my dog), require too much energy to process. That sounds ridiculous, I know, but it's true.

If I receive a text, I'll become teary at the effort involved in reading it, putting it into the context of my relationship with that person, and responding. It seems like a huge responsibility.

When I speak, my delivery has either robotic pauses between words, or I find myself repeating the same word in a sentence several times before moving on. I can't find the words I'm looking for, and often my sentences just trail off without ending, and I'll either give up communicating, or resort to using gestures.

Sometimes I'll be able to read a book aimed at 8-12 year olds ('Anne of Green Gables', for example), other times, I can't read anything.

If I hear a sudden loud noise, such as a sneeze, it will make me feel physically ill, and often emotionally distressed. As a result, I use earplugs, and also keep sunglasses at the ready, due to light sensitivity.

Although my legs feel like they are made of cement, I can almost always walk, although I have an increase in dizzy spells. When I can't walk, I can get around by scooting along on my backside.

Any physical exertion, such as washing my hair, is absolutely out of the question.

My current 'baseline' symptoms, generally experienced no matter what type of day I'm having, are fatigue, involuntary twitches, alternating diarrhoea and constipation, aches in my calf muscles, faintness, tingling feet, mood swings, bladder urgency, abdominal cramping and varying degrees of noise sensitivity and brain fog.

For the first two years after I stopped working, my days were mostly busy; more often than not I'd have an appointment with some type of healthcare professional. For the last 18 months, as I realise certain treatments aren't working, the frequency of appointments has decreased to about one per nine days. With the dwindling of treatment options comes the dwindling of hope, and an increase in alone time. It's a slow form of torture.

The psychological symptoms can pop up at any time, but I am very experienced in dealing with them now, and just grit my teeth while telling myself *"This is not how you really feel – your circumstances aren't any different to what they were 30 minutes ago. Just ride it through."*

Most days I have a superficial (yet real) level of happiness – I laugh, and I can usually find something to look forward to. I have to; I don't have the energy to get myself out of the black hole I could so easily fall into.

I get by by not thinking about any time further than a few months in the future, and by focussing on how proud I am that I have always done my absolute best in dealing with my circumstances, even though I know the scale I measure myself by is not one recognised by the greater community.

I once made the mistake of revisiting Facebook after a six month absence, and was literally breathless at the gaping sense of loss I felt when comparing my life to that of my friends, who have given birth, progressed in careers, enjoyed social occasions, bought expensive ‘toys’ and are blissfully ignorant of how very blessed they are. I don’t go on Facebook anymore.

There is very little comfort for me – I can’t indulge in chocolate or alcohol, for example, listen to music, engage in strenuous exercise to relieve stress, or have a night of partying to blow off steam.

I see family every couple of months, and carefully clear my schedule of any appointments or domestic duties in the days leading up to the events, and the days afterwards.

This thing I live is not really a life – at best, it reminds me of what healthy people experience when waking up with hangovers and staggering around still half asleep. At worst, it’s like a waiting room to death, that I’m going to potentially spend another 40 years - the entire length of my life again - in.

Counting the costs

Financial

In the decade prior to diagnosis, I estimate I spent approximately $80 000 searching for a diagnosis and subsequent treatment.

Since then, I have accumulated treatment receipts to the value of $108 000.

My Income Protection Insurance claim approval allowed me 75% of my wage for a two year period. I therefore lost 25% of my wage for those two years, and 100% of it in the time since, resulting in a gross loss of $127 187.75, excluding any CPI increase.

As a high performer in all my paid roles, it is also likely my career would have progressed further, and at a much quicker pace, had I had the energy to reach my potential.

Due to concerns regarding the possible impact of CIRS on my recovery, I moved house, incurring real estate agent and stamp duty fees. Living in a flat, coastal area, it was difficult to find an elevated house with adequate ventilation that was not susceptible to mould issues, within our price range.

After five months search, we finally found a property that cost just $24 000 than the one we sold (which had increased in value due to renovations). However, it needed modification to allow for appropriate drainage of the block, gutting of a water damaged bathroom, installation of an air purification system and ducting, installation of an awning over the unprotected door that had made the door mat mouldy, and replacement of carpet with floorboards.

We were also advised by our mould remediator to dispose of replace all of our furniture.

The total cost of this exceeded $90 000, even though we tried to limit costs by having Ryan complete as much of the manual labour as possible.

I believe a conservative total of the overall cost of my illness would be well over $400 000.

Despite having no debt just one year ago, Ryan and I now have a $330 000 mortgage, and not much (in most people's terms) to show for it.

Social isolation/exclusion

Most of our family members haven't asked how I am doing, or how Ryan is coping, for at least two years, let alone offered any support. On the contrary, on a number of occasions, different people have tried to shame us during family dinners by challenging us along the lines of "*So, you don't have* any *kids, but you can't even look after* ours *for one night?"*

In another instance, I texted a family member I have supported many times, mentioning how empty my life was. My comment was within the context of the conversation, but it ended that conversation – we didn't speak with any degree of normality for well over a year, and it's never been referred to again.

Ryan and I are not sure why this is, and haven't asked, as I just don't have the energy for a conversation that may turn confrontational.

As far as I know, neither of us have given anyone any reason not to value us (if anything we go out of our way to protect people from knowing how bad things get) but I assume that it's just easier for them to be in denial, then to acknowledge the horrendously relentless battle we're going through, either to limit their own distress, or to avoid feeling obligated to take any action to support Ryan and I.

That's another reason why it's so important that the government step in and take the lead; they don't have the same emotional investment, and should therefore be able to bring our cause through to some kind of resolution with the accountability of professional responsibility, and minus the burden of emotional impact.

I feel deeply betrayed that instead, our government contacts seem to humour us by (eventually) listening to our stories, then simply shrugging.

The lack of interest and support from family means that any social interaction is often superficial; there can be no genuine connection when your circumstances are disregarded. We spend most of the time in the company of family talking about their lives, Ryan's 4WD hobby or the new house.

The only other reason I can come up with to explain this, is that it's almost like for some people there's an attitude that my illness is an embarrassing failing on my part, that people are politely ignoring.

Things are a little better with friends, presumably because my serious illness doesn't threaten their happiness in the same way a family member's would.

They will ask questions, but not to the degree of allowing them any real insight into how bad things are. And I generally don't proactively offer information, for fear of coming across as the Lymie stereotype implied by the government and medical profession; a self absorbed, mentally ill, attention seeking hypochondriac.

The last time I saw a group of friends was January 2015, when I attended a 40th birthday party. At the time my brain had been in a hyper stimulated state for a few months, but I'd missed so many of that group's 40ths, despite the fact they'd thrown me a party for mine, that I decided to attend regardless, to avoid looking self absorbed or ungrateful.

It was a mistake. The party had a fancy dress theme, and my brain struggled a bit with people's disguises. There was also music, bright lights, and many different conversations happening at the same time.

I saw a friend I hadn't seen since prior to my diagnosis, and she asked about my health. My brain tried to cherrypick the relevant bits of information from my history to form a short summary, but it was just too hard, and it was like my brain just slipped to a lower gear and stayed there. Ryan saw how dazed I was, gave me my ear plugs and took me for a walk around the block, but it was too late. My teeth started chattering, and when I tried to talk, my words were all gobbledegook.

We went home, and haven't seen those friends since.

The last time I remember seeing a friend one-on-one was a month later; Ryan had bought this friend and I concert tickets for my birthday, before my brain started running at warped speed. I got through the concert with my trusty earplugs, but became disorientated afterward; it took us over an hour to locate my car.

Since that time over a year ago, I have only been in two social occasions that didn't involve family, both of which were due to Ryan's best friend's engagement. This friend and his family are amongst the very few we've had relatively detailed conversations about Lyme with, so I was able to kind of coast through the events knowing that Ryan had the primary responsibility for socialising, and that if I glazed over or left to go for a nap, people would have some context.

I still receive occasional texts and emails from a vastly reduced group of friends (speaking on the phone can be difficult for me), and I'm in intermittent contact with two Lyme friends – as earlier mentioned, I have otherwise removed myself from that community; it's just too hard to see my pain reflected back at me, and too difficult to avoid the temptation to get involved and further delay my already drawn out recovery from burn out.

I also occasionally hear from the mother of another patient – a whimsical, bubbly girl who had been fulfilling her desire to help others with a Social Work degree at the time she became sick. In early March, her mother contacted me with thanks for the Christmas card I'd sent – her daughter had only recently been in the right headspace to open it. The accompanying present still hasn't been opened; hopefully she'll be able to get enough of a reprieve from her personal hell to open it soon.

Loss of major life opportunities

Unfortunately this illness has struck me during the prime of my life, when I should have been setting the foundations for the rest of my life, with devastating consequences.

- I have missed the opportunity to have my own children, and although at one point Ryan and I had considered fostering in the future, currently there is no reason to realistically expect I will have the stamina to care for an already traumatised child. I am also aware of foster children being removed from older parents, should a younger parent become available.

- My LLMDs have made it clear to me that even if I reach some form of remission, some patients who experienced chronic illness are unable to return to the rigour of their previous lives. Given that my recovery has been much slower than expected, I am unlikely to have the physical and mental resilience required for a challenging career or a busy social life.

At the time I became ill, I was considering more tertiary training – at present, I can't see myself completing any serious degree of study. Should I re-enter the workforce, I assume it will be at a much lower level than when I left, and probably less fulfilling, too.

With that will come reduced capacity to improve our financial situation, and create any degree of security.

- A life isn't only defined by family and work; hobbies and passions also play a part. Unfortunately even if you have the right equipment - Ryan bought me an expensive camera to indulge my photography interest, just before I finished working - you need the energy to pursue these.

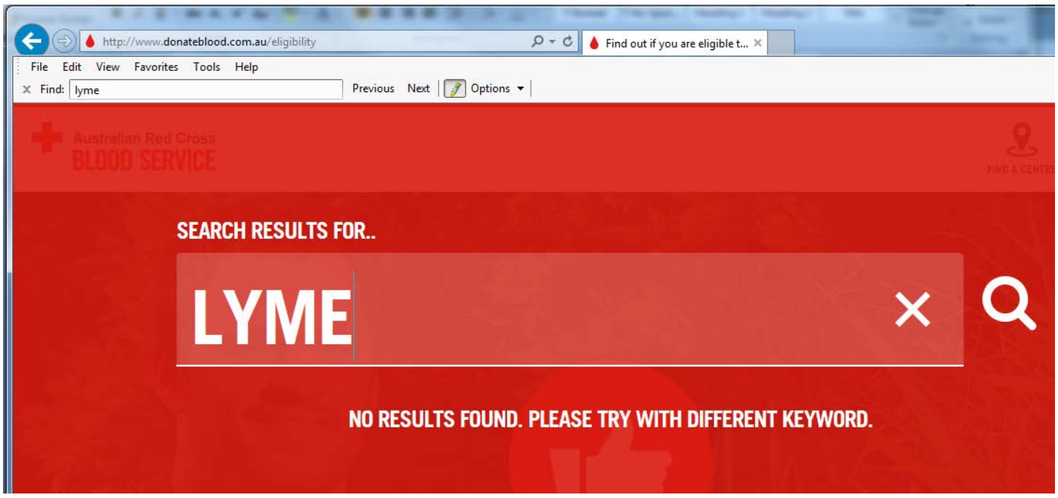
  And wussy though it may sound, I just don't have the energy, even for a sedentary hobby. So that's another missed opportunity for self development and fulfilment.

I guess you could sum it up by saying I feel like I have no purpose; that there's no point to my existence.

<u>Unable to contribute to community</u>

I used to sponsor a child through World Vision, and do volunteer work - now I don't have the financial or physical resources for either.

I can't even contribute via organ or blood donations. I'm not ineligible because I have Lyme – despite the Lyme community expressing their concerns to the Red Cross multiple times, resulting in various contradictory responses, their website currently makes no mention of Lyme.



SEARCH RESULTS FOR..

LYME

NO RESULTS FOUND. PLEASE TRY WITH DIFFERENT KEYWORD.

It does, however, rule me out as I've been diagnosed with Chronic Fatigue Syndrome. The reason given for this is that "*Because we don't know the cause of this serious, debilitating disease, we can't rule out that it is caused by a transmissible infection that medical science hasn't discovered yet.*"[50]

If the irony wasn't so distressing, it would be funny.

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[50] Australian Red Cross Blood Service, *CHRONIC FATIGUE SYNDROME – I HAVE/HAD CHRONIC FATIGUE SYNDROME. CAN I DONATE?*, http://www.donateblood.com.au/faq/chronic-fatigue-syndrome

Unnecessary strain on my marriage

The lives of Ryan and I are entwined – every hurdle I face, is faced by both of us. Every opportunity I've lost is a loss to both of us.

We have a strong marriage, but with little real support and understanding from the majority of those around us, there is a sense of isolation, which would put a strain on any relationship.

Several times, for example, we have been told by friends and family that we are selfish for not having children. These people haven't asked us why we don't have children, or connected the dots themselves, just gone straight to judgement.

Ryan was only 21 when I became ill – almost his whole adult life has been limited by my condition. This guilt I feel associated with this, combined with my sense of uselessness, feeling of being a burden, and mood swings mean that our lives can be an emotional minefield.

Many of the activities that bring people closer together, such as sharing the same meal, having a night out, enjoying a few drinks, or taking a holiday not planned with military precision, just simply aren't possible.

We do go out to dinner maybe twice a year, just for sanity's sake, but it's with an understanding that due to my very limited diet, I'm likely to experience vomiting, diahorrea, severe stomach cramping, mood swings, nausea, exhaustion or a combination of these.

In addition to full time shift work with a long commute, Ryan has had to take on carer duties, which included rising at 4:30am instead of his usual 5:30am, to administer IV antibiotics. It was also necessary for him to essentially take on the role of 'burnout bodyguard', and monitor the amount of time I spent helping patients who weren't lucky enough to have a partner. Given the dire circumstances of some of these patients (see 'Patient Stories'), I sometimes resisted his input, which caused friction.

I love Ryan very much, and I know he loves me, but sometimes I can't help but wonder if it would be better if we'd never met.

Lack of trust in the government and medical profession

Call me naïve if you will, but although I knew prestige and/or family pressure motivate some people to enter the medical profession and the higher ranking areas of the government, I always assumed that they would also have at least some degree of genuine desire/commitment to serve the community.

However, the immoral behaviour and completely lack of compassion I've witnessed by some people in these roles, in the face of measurable evidence of suffering that they admit they cannot explain, is deeply disturbing.

Seriously, it's creepy, and I will never look at people the same way again.

Uncertainty of the future

I used to worry a lot about the future. I try not to, now, because my immediate goal is to regain my health, and endless stress about something outside my control is not conducive to that.

But I can't completely ignore my fears, which include that:

- I will simply run out of treatment options (currently very likely), and therefore, hope

- I will never be well enough to return to paid employment

- even if I am well enough to return to paid employment, no one will want to hire me. Women returning to the workforce after children often lament how difficult it is to find a job. I can only imagine the additional reluctance of employers to hire someone who claims to have had a controversial illness that has repeatedly been publicly dismissed, of which very little is known.

- Ryan, whose immunity is already compromised by Type 1 Diabetes, will become seriously ill, and I'll be powerless to provide him the financial security that he has provided for me

- if something does happen to Ryan (according to Diabetes Australia, Type 1s have a reduced life expectancy of "a little more than a decade"[51]), I will be completely alone

- if I am completely alone, I won't be able to afford to live somewhere in which I feel safe, particularly given the government is still unsure of how to fund benefits for our increasingly aging population.

  And if I'm not somewhere safe, I may be attacked again the way I was in 2003, resulting in further disability and a further decline in independence.

- as time passes, the gap between the experiences of myself and my loved ones will continue to widen, until our relationships pretty much disintegrate due to lack of common ground

- my osteopaenia (which, despite calcium supplements, had worsened in last bone scan) will progress to osteoporosis, and I'll fall and break a bone, but may not be discovered by anyone due to isolation as described above

- that the government will never take my situation seriously, and I'll live out the rest of my days feeling that there is no point to me and what I've gone through; no context through which my suffering has helped others

Recommendations

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[51] Diabetes Australia, *Life expectancy for people with type 1 diabetes increasing*, https://www.diabetesaustralia.com.au/news/13916?type=articles

1) A targeted campaign for reform within the medical community, so that:

- medical professionals are actively encouraged by their peers and authorities to report instances of unusual, chronic illnesses, and are appreciated, rather than ridiculed or persecuted for doing so

- AHPRA becomes more accountable for justifying resource allocation

- AHPRA are investigated for negligence in the case of Bacchus Marsh Hospital and the perceived bullying behaviour of LLMDs. Investigation is also carried out into how they were able to act so inappropriately for so long.

- doctors are held accountable for inappropriate public commentary, such as that documented in this submissions

- serious disciplinary action should be considered for those who fail to act appropriately whilst using the title of Doctor

- doctors are not given leeway to break the law in regards to ACDs, just because they have a different value system to that of their patient

- doctors have a resource (kind of like in the TV show 'House') that they can refer patients to if they have run out of ideas as to how to treat a patient, or what kind of specialist to refer them to. This will prevent them from becoming defensive and lashing out at patients, causing them further distress. As heard in the inquiry, Canada has a dedicated team that look into the illnesses of patients that aren't easily diagnosable.

- doctors are reminded that just because the cause of an illness is unknown, doesn't mean the illness doesn't exist. There was a time when cancer didn't have a name, either.

  Not being able to match a patient's symptoms to a well known condition does not mean that they have Munchausen syndrome or Conversion disorder.

- medical professionals receive further education so that they respond with sensitivity and professionalism to patients with a history of mental illness.

  I have had my prior depression thrown in my face in a strangely triumphant manner by a gastroenterologist as the cause of my illness. When I began to cry in despair of getting appropriate diagnosis and treatment, he actually pointed and me and cried "See, depression!", with victory written all over his face.

  I've also had a nurse sidle up to me when I was visiting a patient in hospital, saying "You do know she has a mental health history, right?" as if that was in any way relevant. People who have had mental illness do not have a magical bubble around them that prevents them from physical illness.

  Granted, anxiety and depression may have physical symptoms, but that doesn't exclude the likelihood that a chronic illness, particularly one with abnormal laboratory results, accompanied by a history of a vector bite, is completely unrelated to their prior mental health status.

After all, if patients with mental illness have had previous physical manifestations, then surely those symptoms have caused stress to their body, possibly making them more susceptible to illness that doesn't have a psychological basis?

- nurses have the ability – in fact, the responsibility – to report doctors who are not completing due diligence in their role, and are provided with mechanisms to avoid acts of bullying/retaliation for doing so.

  Presumably this already exists, but it's not very successful. I've heard patients report of nurses whispering apologies to them for the way they have been treated, along with explanations that they are powerless to do anything about it.

- The culture that has resulted in doctors refusing to disagree with colleagues, sometimes at the expense of a patient's life, is destroyed, and analysed to identify the root cause, and how to prevent it from re-emerging

  Neurosurgeon Dr Charlie Teo has gone on the record about this culture,[52] recounting a conversation with a "*surgeon I have a lot of respect for*." Dr Teo described being approached by this surgeon, at the request of his colleagues, to tell him "*Charlie, you've got to stop doing this, you're really pissing people off…Stop operating on patients that others have called inoperable*." Dr Teo said then showed the surgeon a child's xray; they both agreed the tumour present was operable. He then asked "*Do you want me to now call up that mother and say that that tumour is inoperable, and I am going to let your child die*?" The surgeon replied "*Yes, I do that every day.*" Dr Teo concluded "*Every day he lies, so he doesn't piss off his colleagues, and he doesn't give opinions that are different to someone else's opinion."*

  This behaviour, of placing ego before death, is I believe, also influencing the Lyme community. It is alluded to in the bullying that LLMDs report. It's also implied Submission 78 – and probably others. In this submission, the patient says a dermatologist diagnosed her, but "*He did also say that he would never stand up and declare this in Public though"*

  It is one of the most toxic things imaginable, that someone who has accepted the task of healing would intentionally stand by and allow suffering and fatalities, to avoid hurting egos that are clearly out of control. It is breathtakingly awful, and it needs to be addressed as a matter of urgency.

2) An in-depth government review, which is then released to the public, covering:

- why the government has not specifically addressed evidence of Borrelia, which is dated back to the 1950s, and the reports of human diagnoses dating back to the 1980s

- why the government has focussed solely on the Russell and Doggett study, particularly given its flaws

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[52] Ahn Do's Brush with Fame, *Episode 3, Season 1, Charlie Teo*, 7 Sept 2016, http://iview.abc.net.au/programs/anhs-brush-with-fame/DO1523H003S00

- whether a culture of bullying and intimidation exists within the research profession, and if so, identification of the root cause, and appropriate action to destroy this and ensure it does not re-emerge

- why even patients who have contracted their illness from a known tick bite in countries that recognise the presence of Lyme, have had difficulty getting appropriate treatment

- why government representatives including Federal Health Minister Tanya Plibersek, NSW Health Minister Jillian Skinner and NSW Director of Health Protection Dr Jeremy McAnulty repeatedly refused professionally worded requests from a credible, registered association for a meeting to discuss their concerns.

- why despite this refusal, Dr Jeremy McAnulty immediately caved when 70 patients protested in front of NSW Health.

- why the government meetings of April 2011 were not made public knowledge, until the LDAA submitted a Freedom of Information inquiry

- what steps the government will take to ensure that officials are appropriately receptive to communities with health concerns in the future

- why the NSW Health Lyme disease factsheet is so poorly written (see ‘*Cherrypicking of information on the government’s Lyme disease factsheet*’)

- why the Office of Health Protection has failed to live up to its mission statement in relation to Lyme patients, to the degree that resulted in Senator Reynolds stating to Dr Lum that “*you have spent four years discussing something that you have repeatedly said does not exist here in Australia at all, and you have not yet looked at anything else in that whole time that has come up.”*

- why the CACLD took no public action when its RCPA representative Prof Graves, by the RCPA’s own admission, chaired the committee that released the ‘Position Statement’, despite the questionable timing

- why the CACLD failed to distance itself from Prof Graves when, after the committee concluded, he made statements that he couldn’t possibly back up, including that patients were paying overseas laboratories to give them the results that they wanted, and that patients definitely did not have Lyme disease.

  His commentary reflected poorly on the legitimacy of the CACLD, and yet they failed to respond.

- how, despite failing to address Prof Graves’ behaviour as outlined above, were the CACLD able to find the time to contact the very small Sarcoidosis Lyme Australia organisation, and convince them that their online petition for government was inappropriate given the CACLD’s existence, and that they should remove it as a “goodwill gesture.”

- whether a culture of bullying, intimidation and/or bribery has led to the entirely unsatisfactory responses of the government to date, and how this should be addressed

- why doctors are so confident in their ability to break the law without consequence in instances such as my example regarding Advance Care Directives occur? And why is their confidence justified? What is being done to address this?

- why was a Lyme patient of [hospital name redacted] told in April 2014 that she was going to be discharged, without an ACAT assessment having been completed, nor a care plan put in place, particularly when staff were aware that the patient had no carer, nor confirmed accommodation, Why was this breach of the hospital’s Patient Charter only addressed when the Lyme community mobilised to send letters of concern to hospital CEO [name redacted] and Patient Liaison Officer [name redacted] on 22 April?

- why has the government not addressed concerns regarding the priority of tick-borne diseases for research grants.

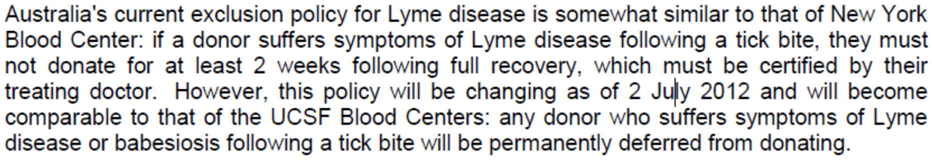
  The government swung into action using its own resources, at the very thought of its citizens potentially being exposed to the Zika virus, yet there is definitely a Lyme-like illness already here, that many patients report has resulted in an unusual high incidence of miscarriages, which is obviously a more severe outcome than the birth defects that Zika can result in.

- why has the government failed to act on the learnings gleaned from the global response to the HIV infection?

- why does the Red Cross exclude people with CFS from donating blood, due to the fact that *“we don’t know the cause of this serious, debilitating disease, we can’t rule out that it is caused by a transmissible infection that medical science hasn’t discovered yet*”**,** given that that could also be considered true of the Lyme-like illness?

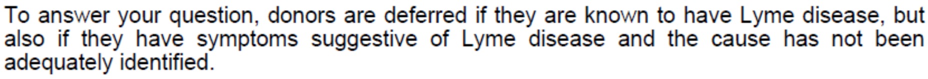
- Why does the donation eligibility criteria of the Australian Red Cross Blood Service (funded by federal, state and territory governments) currently make no mention of Lyme, despite:

    - the following quote in a letter sent by the Red Cross to a Lyme patient concerned about possible infection via donated blood, dated 12 June 2012.



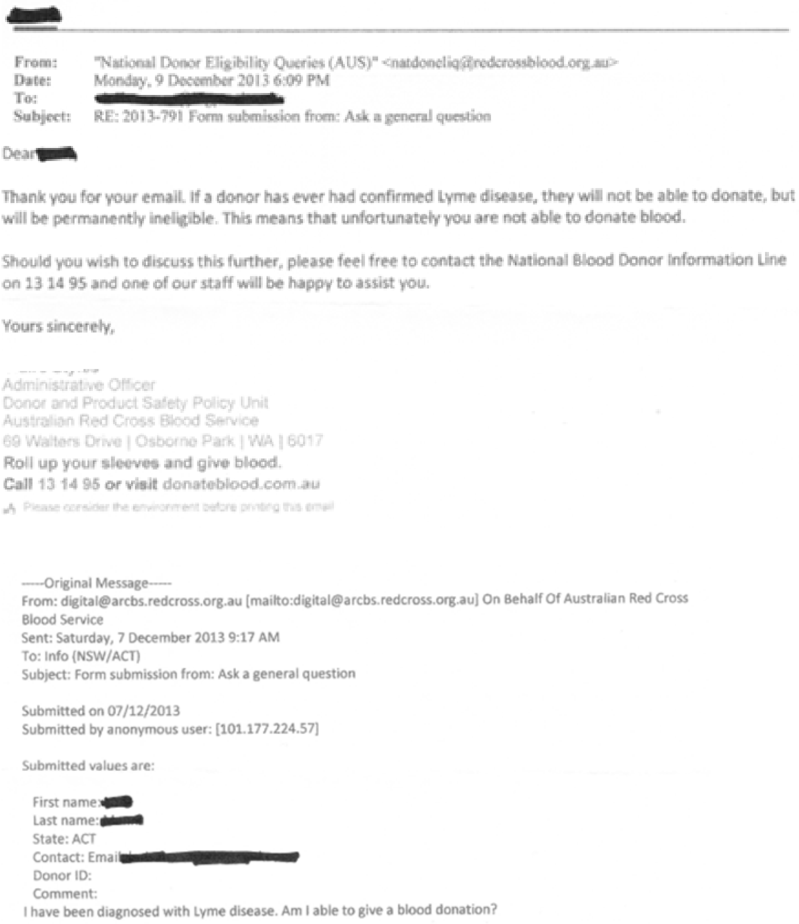
Australia's current exclusion policy for Lyme disease is somewhat similar to that of New York Blood Center: if a donor suffers symptoms of Lyme disease following a tick bite, they must not donate for at least 2 weeks following full recovery, which must be certified by their treating doctor. However, this policy will be changing as of 2 July 2012 and will become comparable to that of the UCSF Blood Centers: any donor who suffers symptoms of Lyme disease or babesiosis following a tick bite will be permanently deferred from donating.

    - this excerpt, from a letter sent to another patient, dated 7 March 2013:



To answer your question, donors are deferred if they are known to have Lyme disease, but also if they have symptoms suggestive of Lyme disease and the cause has not been adequately identified.

- o This response to an online inquiry, dated 9 December 2013



[redacted]

From: "National Donor Eligibility Queries (AUS)" <natdoneliq@redcrossblood.org.au>
Date: Monday, 9 December 2013 6:09 PM
To: [redacted]
Subject: RE: 2013-791 Form submission from: Ask a general question

Dear [redacted]

Thank you for your email. If a donor has ever had confirmed Lyme disease, they will not be able to donate, but will be permanently ineligible. This means that unfortunately you are not able to donate blood.

Should you wish to discuss this further, please feel free to contact the National Blood Donor Information Line on 13 14 95 and one of our staff will be happy to assist you.

Yours sincerely,

Administrative Officer
Donor and Product Safety Policy Unit
Australian Red Cross Blood Service
69 Walters Drive | Osborne Park | WA | 6017
Roll up your sleeves and give blood.
Call 13 14 95 **or visit** donateblood.com.au
Please consider the environment before printing this email

-----Original Message-----
From: digital@arcbs.redcross.org.au [mailto:digital@arcbs.redcross.org.au] On Behalf Of Australian Red Cross Blood Service
Sent: Saturday, 7 December 2013 9:17 AM
To: Info (NSW/ACT)
Subject: Form submission from: Ask a general question

Submitted on 07/12/2013
Submitted by anonymous user: [101.177.224.57]

Submitted values are:

First name: [redacted]
Last name: [redacted]
State: ACT
Contact: Email [redacted]
Donor ID:
Comment:
I have been diagnosed with Lyme disease. Am I able to give a blood donation?

- Why have the Australian Red Cross Blood Service documented concerns about other tick borne infections such as Babesia, but not Borrelia?[53]

- What commitment will be made to the ongoing investigation into Lyme, until adequate causes are fully identified and effective treatment (in the opinion of patients, as well as authorities) is readily available?

- Once investigations have reached a resolution satisfactory to patients, will compensation be considered for living patients and bereaved families of deceased patients?

  (Note: I acknowledge that in the Lyme community the topic of compensation is a controversial one; many patients understandably want to take money out of the equation for fear it will muddy the waters and cast further doubt on our motivations.

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[53] Australian Red Cross Blood Service, *Monitoring Emerging Diseases: Hepatitis E, Babesia, Q Fever*, http://www.donateblood.com.au/research/monitoring-emerging-diseases

> However, it appears to me as a layperson, that a staggering amount of incompetence and lack of duty of care has been demonstrated by the government, despite a precedent set regarding the response to the emergence of the HIV infection.
>
> Given the government failed the HIV patients, then in turn to Lyme patients, I have no confidence that patients of another illness will not face the same fate in future. It seems professional responsibility and moral obligation aren't significant motivators for the government, leaving us with, in my opinion, little alternative to hitting them with impacts to the budget.)

A final note

Thank you for reading this unexpectedly long submission! I have tears of joy in my eyes that I have managed to write an account that represents my experiences. I have huge pride and relief in reviewing it, and thinking "Yep, this is *exactly* my voice!"

It has occurred to me, however, that given how relatively articulate this document is (if I do say so myself!), some readers might question the validity of my claims of chronic 'brain fog'. I would therefore like to explain that my biggest strengths have always been my written communication and analytical skills, hence my ability to stay in the workforce so long. (In the last seven years of my career, in fact, I leaned very heavily on these qualities, firstly in my role as a document/process writer, and then as a Business Analyst.)

So whilst I do suffer from chronic brain fog, my underlying intellectual profile remains the same, and yes, there are moments of lucidity, particularly when I am alone, and don't have the movements, conversation and actions of others to process.

Whenever I have experienced one of those occasions over recent months, and had a thought relevant to this submission, I've jotted it down. This document is basically a compilation of those thoughts, written over the period of three weeks.

In order to maintain the mental and emotional stamina required to fuel the documentation of my submission, I've done that thing of forcing myself into a heightened state of stress, so that I can coast along on the resulting adrenaline. This has been at a significant cost to my health, though; on average, I've only been able to sleep approximately two-three hours per night. This is not because I'm tossing and turning in bed with emotional angst, but because once I've caught the adrenaline wave, it's pretty much impossible to get off it; sleep is so unlikely that I don't even bother going to bed.

It has taken my body literally months to settle down again from the impacts of this.

Given how desperately I want to regain my life, it's difficult for me to abuse my body in this way. But I believe it's a necessary sacrifice, to deliver you all the ammunition I can, so that this battle can be fought as fully as possible.

I would like to close by saying that although I have those aforementioned tears of joy, I also have a corresponding weight in my heart, that is protecting me from seriously hoping that the voices of the brave, raw, generous and embattled Lyme community are going to be heard and acted upon.

Realistically, I don't think these submissions and the Senate hearing are going to result in any significant changes for Lyme patients. Even if the government is finally shamed into some form or action, I have learnt through working on the International WWLP committee that even in countries in which Lyme is recognised, treatment and support is often sorely lacking.

Given our government's complacency to date, I see no reason why it would take the lead on an issue other countries are dragging their feet on.

I would like nothing better than to be proven wrong though; in fact, it would be a dream come true.

So please - *please* - prove me wrong; please help resolve what is to date a very ugly chapter in our government's history, and a very traumatic one in the lives of patients.

This submission is dedicated to the memory of Scott Chant.

Although I never had the privilege of knowing Scott, his searingly raw account inspired even greater determination to fully rip off my own Band Aid.

My most sincere and heartfelt condolences to his family.

Also, with inexpressible thanks to Senator John Madigan – you are quite simply a superhero.