

Lyme disease: Australian patient experience in 2012



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About the Lyme Disease Association of Australia (LDAA)

The Lyme Disease Association of Australia (LDAA) is a non-profit organisation providing support and advocacy for people and families living with Lyme disease. The LDAA is committed to educate and lobby government, doctors and the community about Lyme disease by connecting and sharing knowledge and international developments, treatments and other Lyme communities.

Acknowledgments

We extend our appreciation and thanks to Ms Melitta Marr who developed the Australian patient survey which has enabled Australian Lyme patients to unite and be counted.

Foreword

The first clinical case of Lyme disease was identified in Australia in Branxton (near Maitland, NSW) in 1982, yet thirty years later many Lyme disease patients struggle to obtain diagnosis and appropriate treatment in Australia. As well as acquiring Lyme disease locally, many Australians have acquired, and continue to acquire, Lyme disease overseas, and yet remain unable to obtain a diagnosis and treatment on their return to Australia.

Unfortunately very little research is conducted on Lyme disease in Australia, and none on the experience of Lyme disease patients. This inaugural survey report by the Lyme Disease Association of Australia sheds light on the experience of Lyme disease patients in Australia, and recognises that their experiences are markedly different to those of similar diseases. Lyme disease patients are regularly denied treatment by local doctors, specialists, emergency departments and allied health professionals, entirely because they have Lyme disease – this level of discrimination, harassment and inability to get adequate treatment bares hallmarks of how HIV & AIDS patients were treated by the medical establishment in the 1980's.

It is a sad indictment on our society that we did not learn from the HIV/AIDS community's experience, and that Lyme patients must endure similar experiences, thirty years later, simply because they uttered two controversial words – 'Lyme disease'; even if they acquired it overseas.

Today, in Australia, there are a growing number of people diagnosed with Lyme disease and most are significantly impacted by their illness. Because there has been little action by the local health authorities, except to deny the existence of Lyme disease in Australia, the LDAA is taking action on behalf of all Lyme sufferers, irrespective of where they acquired their disease so that their voices and their experiences may be heard.

This survey represents the first consolidated collection of data from the Australian Lyme disease patient community – our goal is to continue the collection and analysis of this data, so that over time we will have a longitudinal study of the experience of Lyme disease patients in Australia.

I encourage doctors, allied health professionals, health policy officials and the government to read this report and take note of the experiences of Lyme patients – we desperately need to make changes to how Lyme disease patients are treated – both medically and personally – to improve their health outcomes and to move the treatment of Lyme disease into the 21st century.

Nikki Coleman
President
Lyme Disease Association of Australia

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Executive Summary

This report provides data on the first survey to examine the Lyme disease situation in Australia from a patient perspective. It focuses on how Australian's are acquiring Lyme disease, how they are being diagnosed, or not, and how they are being treated once they have a formal diagnosis of Lyme disease. For Lyme disease patients in Australia, **the situation is dire**.

Lyme disease is the largest and fastest growing tick borne illness in the world. It is commonly transmitted to humans through the bite of an arthropod vector infected with the bacteria (*Borrelia burgdorferi*). Lyme disease has three stages that are characterised by a progressive worsening of symptoms as the bacteria disseminates throughout every organ and system in the body. Lyme disease is frequently called *the great imitator* because it can mimic many other diseases, especially neurodegenerative diseases like Multiple Sclerosis, Parkinson's disease and Motor Neurone disease (ALS) among others.

Obtaining a diagnosis of Lyme disease is fraught with inconsistency in the Australian medical system. Lyme disease is not even considered, in a differential diagnosis, by Australian doctors because of a long standing position held by Australian governments who provide advice to the medical community that 'Lyme disease does not exist in Australia'. There is dated research about competent vectors and hosts capable of transmitting Lyme disease; and as Lyme disease is not mandatorily notifiable there is no coordinated surveillance. Without a contemporary epidemiological study there is little evidence to support the argument that Australia is the only continent on earth that does not have this vector borne disease.

The patient experiences examined in this report tell a very different story with many Lyme sufferers able to report their actual bite location and subsequent onset of their illness right here in Australia. There are also cohorts of Australian Lyme patients who have never left the country. For many patients, reaching a correct diagnosis is a long process. On average it takes up to six and a half years from the original bite to obtain a diagnosis due to a lack of public and medical awareness. Without a specific Lyme disease education campaign within the medical community, it means that all Australians at risk of acquiring Lyme disease are likely to progress to the chronic stage before they are properly diagnosed. The situation is unacceptable.

The testing for Lyme disease is also controversial. Testing in Australia primarily relies on two specialist laboratories that test for antibodies against *Borrelia* strains that are not sensitive enough or may not be present in Australia. As such, Australian patients are being tested for strains of *Borrelia* that they may not be infected with, hence a low rate of positive tests. Patients that can afford it send their blood to overseas reference laboratories to confirm their clinical diagnosis. There is considerable speculation that an Australian strain of *Borrelia* exists which has not yet been isolated for commercial testing purposes. Research into the presence of an indigenous strain of *Borreliosis* is urgently required.

Like diagnosis and testing, the treatment of Lyme disease is also a controversial issue. There are two sets of opposing guidelines that are used for the treatment of Lyme disease emanating from the United States. Research about optimal treatments is often inconclusive, which further undermines the validity of the treatment guidelines. The Australian position relies on the advice that "most cases of Lyme disease can be treated successfully with a few weeks of antibiotics". The Australian Lyme patient experience provides an opposite view.

Australian patients have a dismal story to tell in respect to being diagnosed and treated for Lyme disease. They report extensive difficulty in finding a treating doctor with many travelling an average of 236km for treatment and some being forced overseas. They are being treated using a number of traditional and alternative methods, usually by more than one doctor. The majority of patients are undergoing treatment for one or more co-infections which makes their treatment longer and the outcome less certain.

Patients also reported that Lyme disease is lowering their quality of life; sadly this was a common theme. Many patients report the personal consequences of living with Lyme disease, from the significant decline in their quality of life, the deficits in their functionality, the dwindling social connections and the increasing social isolation exacerbated by having a long term illness where recognition and education is almost non-existent. It impacts their work life and their ability to maintain employment or schooling. The major decline in the health of Australian Lyme patients are comparable to someone living with type 2 Diabetes or a recent heart attack; their future is grim.

There is a considerable financial burden upon Australian Lyme patients who report having to give up their work due to declining cognitive function which in turn impacts upon their ability to afford health care and ongoing treatment. Many of these costs might have been avoided if patients were tested appropriately, diagnosed promptly and treated accordingly for Lyme disease, before it became chronic.

This report provides evidence that Australian Lyme patients are being misdiagnosed, mistreated and misunderstood by the medical community, allied health professionals and the Government. Australian Lyme patients face discrimination every day in obtaining appropriate diagnosis, in the availability of testing services, in accessing medical professionals who will treat them and in the economic burdens they are enduring in the pursuit of restoring their health.

There exists a serious gap between the medical community's acknowledgement of Lyme disease and the reality of the Australian situation as presented in this study; **it requires immediate attention.**

Key findings

Demographics

- Lyme disease is affecting **largely female** (73%) and **predominantly adults** over 18 years of age (90%) with the highest proportion being 46 or older.

Transmission

- **Not all patients (70%) recall a tick or other bite**; Of those bitten, the **majority of patients (79%) report being bitten in Australia**; **25% of them have never left the country**;
- A minority of patients (20%) **acquired Lyme disease congenitally**; and a further cohort (4.7%) report suspected sexual transmission;

Symptoms

- The **presence of flu like symptoms was reported by 84%** of participants; only **50% report they had a rash**;

Diagnosis

- The **majority (64%) are infected with one or more co-infections** as well as Lyme
- **Almost all patients (99%) report one or more other medical conditions** on top of their Lyme disease;
- In the majority of patients (85.7%) **blood tests formed all or part of their diagnosis**; only (3.5%) were diagnosed on the basis of a bulls eye rash; and (10.7%) were diagnosed on their clinical symptoms;
- Time between bite to **diagnosis takes an average of six and a half years**; the outcome means that **80% of Australian patients will progress to chronic Lyme disease before they are even diagnosed**;
- More than 80% report seeing **4 or more Doctors prior to obtaining a diagnosis**;

Testing

- 66.5% of report their blood tests were positive for Lyme disease; 33.5% reported they were negative; **the ratio of negative vs positive tests is higher in Australia**;
- Australian patents (60%) have sent their blood to labs outside Australia;

Treatment

- The majority **(86%) are currently undergoing treatment for Lyme disease**; and some patients used the survey to seek advice on how to locate a doctor who could treat them
- **75% respondents report difficulty in finding a doctor** who would treat them;
- A minority of patients (43.2%) report being treated by a single doctor; the majority (56.8%) are undergoing treatment by one or more types of physicians
- The majority patients (74.5%) report their primary physician treating Lyme disease is located in Australia; 25.5% reported their primary treating physician is outside Australia;
- **48% of patients are travelling distances of more than 100km**; with a further 23% travelling over 500km;
- 9% of patients report they had travelled overseas for treatment;
- **The average distance Australian Lyme disease patients are travelling to see their treating Doctor is 236km.**

Patient impacts

- The majority of patients (67%) report taking **extended time of work or school** due to Lyme disease;
- **Nearly half (46%) have had to quit their jobs**; only 25% report receiving sickness or disability benefits;
- **38% of patients report having suicidal thoughts.**

Introduction

About Lyme disease

Lyme disease is the largest and fastest growing tick borne illness in the world. Lyme disease is an infection caused by a bacterium known as *Borrelia burgdorferi*, a spirochete (Figure 1), that is transmitted to humans through the bite of a vector (usually a tick) infected with the bacteria. It can cause mild, moderate or severe symptoms, and if left untreated can be fatal.

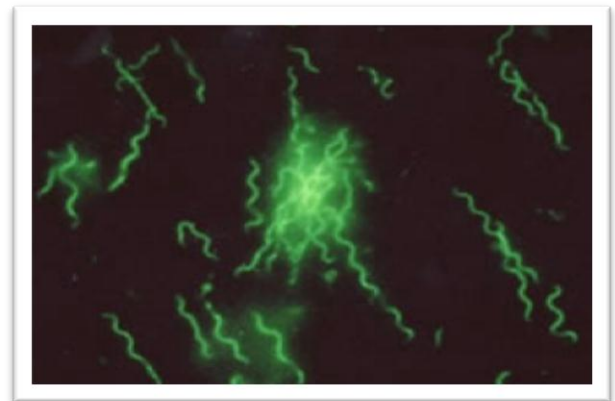


FIGURE 1: BORRELIA BURGDORFERI -SPIROCHETE

Lyme disease has three stages: early (1- 4 weeks), disseminated (1- 4 months) and chronic (5 months or longer). These stages are characterised by a progressive worsening of symptoms as the bacteria disseminates throughout every organ and system in the body. Late stage or chronic Lyme disease is said to occur several months to years after acquisition.

Lyme disease is frequently called *the great imitator* because it can mimic many other diseases such as Multiple Sclerosis, Parkinson's disease, Motor Neurone disease (ALS), Chronic Fatigue Syndrome, Fibromyalgia, Guillain-Barre Syndrome, Juvenile Rheumatoid Arthritis, Lupus, Alzheimer's disease etc. Lyme disease can affect any organ in the body including muscles and joints, the heart, gastro-intestinal system & neurological system (including the brain).

The Australian situation

This Report presents the Australian situation from the findings of an online survey, conducted by the Lyme Disease Association of Australia (LDAA). The survey was developed by drawing from similar patient based questionnaires used in Lyme advocacy and support organisations, primarily in the United States.

The survey was conducted with Polldaddy, an online survey software program, and accessed through the LDAA website. The survey was launched in July 2011 and ran for a year concluding on 26 July 2012. The LDAA promoted the survey on its own News page and through emailing its list and by posting links on the LDAA Facebook group page. The online support groups 'AussieLyme' on Yahoo; 'Aussie Lyme' and 'Lyme Australia and Friends' on Facebook posted information about the survey and provided survey links to their members.

Participation in the survey was voluntary and limited to those who could access it online. No paper surveys were provided to respondents. Respondents were not required to disclose their identity; however 59% of respondents choose to do so. All data reported in this study has been de-identified to maintain respondent confidentiality.

It is the first survey to examine the Lyme disease situation in Australia from a patient perspective. It focuses on how Australian's are acquiring Lyme disease, how they are being diagnosed, or not, and how they are being treated once they have a formal diagnosis of Lyme disease. For Lyme disease patients in Australia, the situation is dire.

Respondents

A total of 339 people responded to the survey. A number of responses have been excluded from reporting as they were duplicated (17); too incomplete for useful data analysis (6); or were offensive (2). In addition some respondents did not meet the survey criteria as they reported living somewhere other than Australia (6); or reported they had not 'yet' been formally diagnosed with Lyme disease (44); or did not answer the question (40).

Therefore the study is narrowed to 224 respondents who report they reside in Australia and as of July 2012, had been formally diagnosed with Lyme disease.

Demographics

All survey participants were asked their gender, age and where they live. Table 1: Age & gender profile of respondents reports the age and gender profile of Australian Lyme disease patients as largely female (73%) and predominantly adults over 18 years of age (90%) with the highest proportion being 46 or older.

TABLE 1: AGE & GENDER PROFILE OF RESPONDENTS

Age groups	Female	%	Male	%	Total	%
0 - 18	16	7.14%	6	2.68%	22	9.82%
19 - 35	22	9.82%	11	4.91%	33	14.73%
36 - 45	53	23.66%	8	3.57%	61	27.23%
46 - 55	42	18.75%	21	9.38%	63	28.13%
56 and over	31	13.84%	14	6.25%	45	20.09%
Total	164	73.21%	60	26.79%	224	100.00%

The figures reported here vary widely to other areas of the world where the Lyme disease age and gender profile is different, especially in relation to children. It is highly probable that children are significantly unrepresented in this survey. For example, the United States Centres for Disease Control and Prevention (CDC) profile cases by age and gender from 2001- 2010 and report a higher male (53%) to female ratio (47%) and a much younger cohort of patients (33%) are under age 20. The CDC state the reported cases of Lyme disease are 'most common among boys aged 5- 9' (Centers for Disease Control and Prevention, 2012).

European studies indicate the two groups most at risk of tick borne disease are children 5-9 years old and adults 50 – 64 years. Additionally females are reported to have a slight preponderance to Lyme disease than males with a range of 54 – 60% reported for many European countries. A 2009 epidemiological study conducted, in Europe, estimated there are 85,000 new Lyme disease patients annually (Hubalek, 2009).

The United Kingdom's Health Protection Agency (HPA) reports people of all ages and genders are equally susceptible to Lyme disease in the UK. The highest reported rates are occurring in people aged 45 – 64 followed by a younger cohort of 24 – 44 years (Health Protection Agency, 2012).

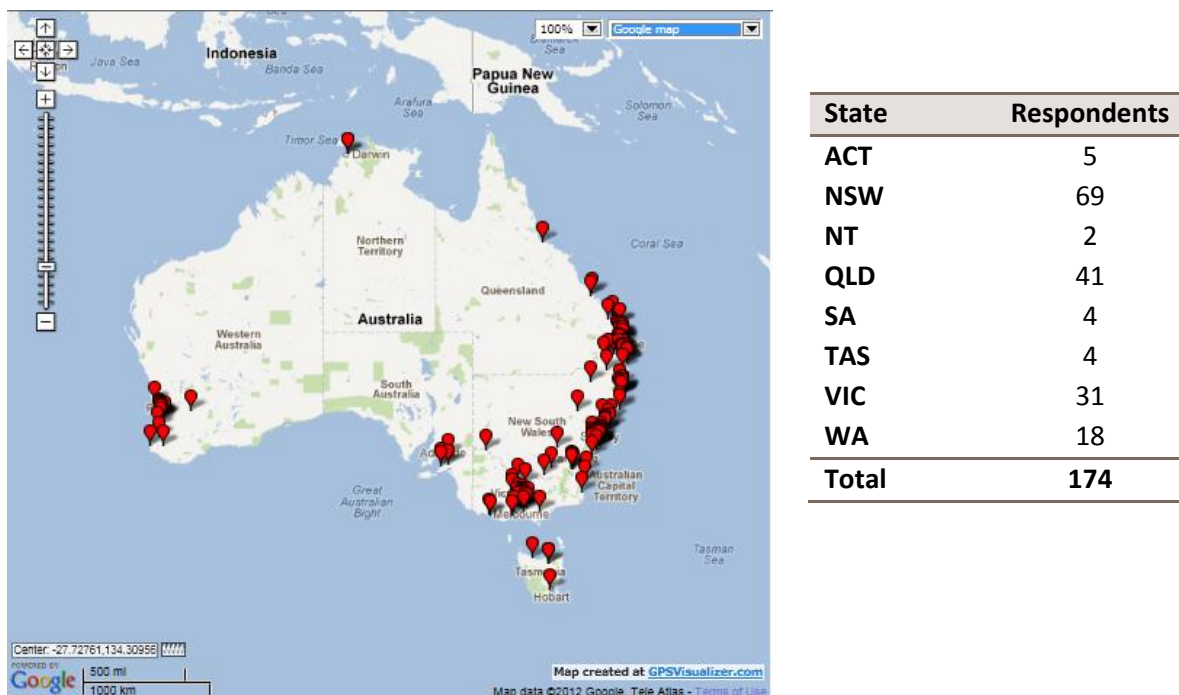
It should also be noted that Lyme disease is not a mandatorily notifiable disease in most countries so is likely to be underreported. In fact the CDC readily acknowledges that Lyme disease is significantly underreported and that the cases of Lyme disease are likely to be 10 times higher than reported.

In addition, the data collection method for the survey was online only, as such it is likely to be skewed to females due to the preponderance for female participation in social networking sites (Sensis, May 2011).

Geographical location of respondents

A total of 174 survey participants provided their current residential location; Figure 2 presents the geographical distribution in Australia which is predominantly coastal areas.

FIGURE 2: GEOGRAPHICAL LOCATION OF AUSTRALIAN LYME PATIENTS



Transmission of Lyme disease

Bites

Research indicates that only 30- 40% of people remember a tick bite that preceded the onset of their symptoms that lead to a diagnosis of Lyme disease. Participants were asked whether they recalled a tick or other type of bite; 142 (70%) reported they recalled a bite and 63 (30%) did not. Of those who recalled a bite, they reported bites from Ticks, Mosquitos and Fleas as indicated in Table 2.

TABLE 2: BITES TYPES REPORTED

What were you bitten by?	
Tick	129
Tick, Mosquito	5
Tick, Mosquito, Flea	2
Tick, Mosquito, Flea, Other	1
Tick, Mosquito, Other	3
Tick, Other	4
Mosquito	1
Total	145

Respondents who reported 'other' were asked to name the source of their bite. They reported bites from a Mouse, Bird Mites, Spiders, Leeches, Wasps, Bed Bugs and Head lice.

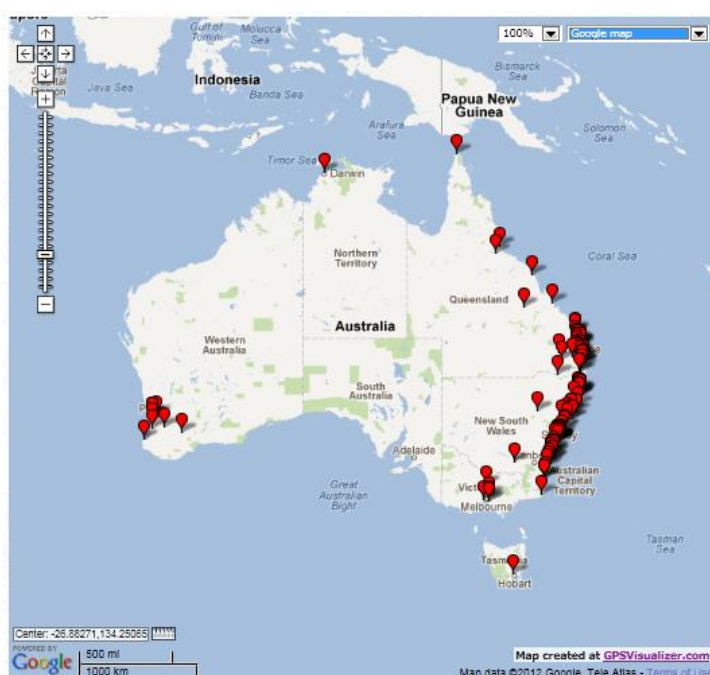
Locality of acquisition

Propagated primarily by the NSW Ministry of Health (NSW Health), there is continuing controversy about whether Lyme disease can be acquired in Australia. Few other governments have taken a position on Lyme disease and instead defer to information published by NSW Health. Their most recent *Lyme disease Factsheet*, states "although locally-acquired Lyme borreliosis cannot be ruled out, there is little evidence that it occurs in Australia. There is a continuing risk of overseas-acquired Lyme disease being imported into NSW" (NSW Ministry of Health, 2012).

This position has been explored in the patient survey and participants were asked a series of questions about their bite location and their travel histories.

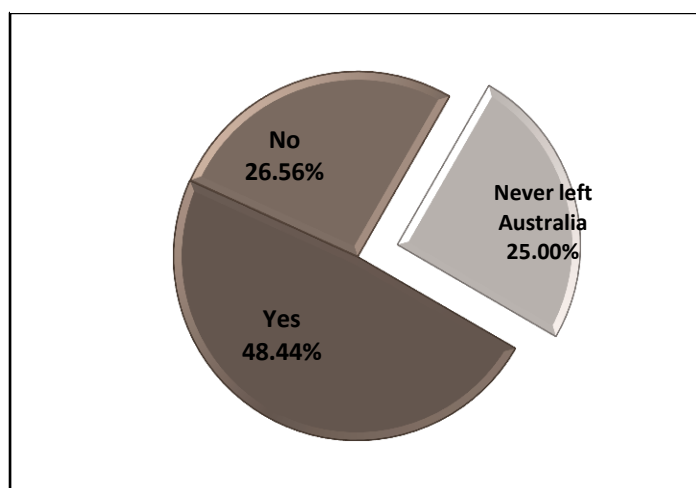
Participants who reported they recall a tick or other bite were asked the geographic location of where they were bitten. A total of 133 respondents (79%) indicated they were bitten in Australia at the locations plotted in Figure 3.

Figure 3: Geographic locations when bitten



State	Respondents
NSW	78
NT	2
QLD	36
TAS	1
VIC	6
WA	10
Grand Total	133

Figure 4: Travel status of Australian Lyme patients



Participants who reported being bitten by a tick, or other vector, and who reported they were bitten in Australia were asked if they had ever been out of Australia prior to becoming ill; 66 (51.5%) respondents said No and 62 (48.4%) said Yes. Exactly 25% of respondents reported never leaving the country, referError! Reference source not found..

A further 35 respondents (20.8%) reported they were bitten while travelling

overseas in the countries indicated in Table 3. So there is indeed a cohort of patients in Australia with 'overseas-acquired' Lyme disease, however these are in the minority (21%) of Australian patients who participated in the survey.

TABLE 3: INTERNATIONAL BITE LOCATIONS

Where were you when you were bitten?	
Africa	2
Asia	6
America (North)	11
Europe	14
Oceania	2
Total	35

Alternative forms of transmission

In an open question, participants were asked to identify how they contracted Lyme disease if it was not acquired from a bite. Of the 63 (30%) of respondents who stated they did not recall a bite, 26 (41%) did not know how they acquired Lyme disease and 25 (39%) offered alternate explanations. We examined the statements made by each participant and classified them into relevant groups, reported in Table 4.

TABLE 4: ALTERNATIVE FORMS OF TRANSMISSION

If you contracted Lyme Disease, but not from a bite how did you contract Lyme disease?	
Possibly Congenital / Congenital	11
Congenital & new tick bite	2
Possibly from raw goats milk	1
Possibly pet mouse	1
Possibly sand flies	1
Possibly sexual transmission	9
Unknown	26
Total	51

Of significance is the 13 (20%) of respondents who report their Lyme disease was acquired congenitally, either in their mothers uterus or via breast milk and in two cases further complicated by new tick bites.

While a recent article (Stanek, 2011) discounts the possibility of Lyme disease being acquired congenitally, it relies upon data that is more than a decade old. The CDC recently reported a case study highlighting the potential of congenitally acquired spirochaetal disease in a new born baby (Centers for Disease Control and Prevention, 2012). However there is little specific research into congenitally acquired Lyme disease and no scientific studies conducted on the long term health effects of those children who may have been exposed in-utero or via breast milk.

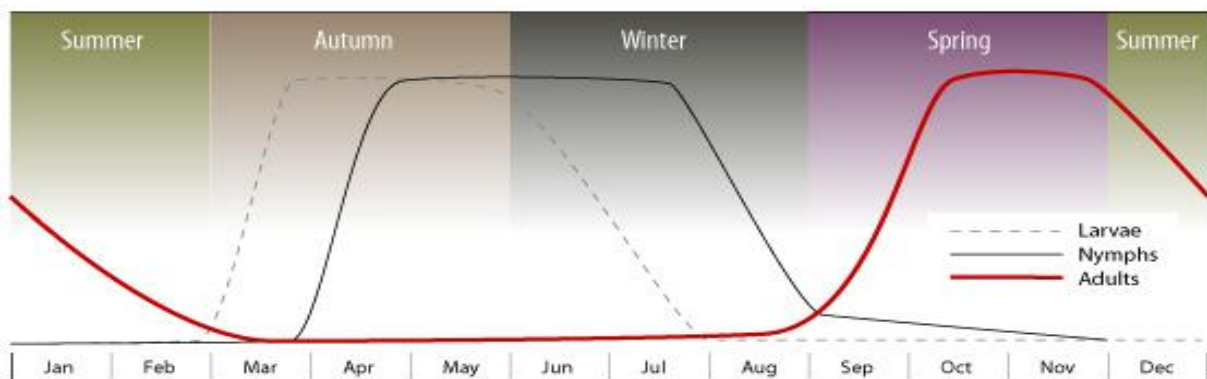
Another alternative form of transmission highlighted in this survey is that of sexual transmission reported by 9 (4.7%) of participants. While there is considerable speculation about the possibility of sexual transmission among patients, as yet there is little evidence to support the transmission of *Borrelia* sexually. The CDC proposes people are at higher risk of acquiring Lyme disease because they occupy the same environment where infected ticks are present.

Interestingly, by cross referencing information provided by participants we have established that, in the cohort responding to the survey, there are 10 families with Lyme disease. This includes male and female adults and in half the cases, children too.

Seasonality of transmission

Dated studies on the seasonality of the Australian Paralysis Tick (*Ixodes holocyclus*) report that that ticks prefer an ambient temperature of 27°C and high humidity to thrive (Clunies-Ross, 1935). Because of this ticks are more prevalent at certain times of the year and concurrent wet seasons enable thriving tick populations. In northern Australia, ideal ambient temperatures and humidity exists year round enabling a thriving tick population and the potential for year round tick bites. A graphical depiction of the occurrence and life cycle of the Paralysis Tick in Australia is shown in Figure 5. More recent data suggests a shifting of the seasons with the Paralysis tick being reported almost year round (Virbac Australia , 2012).

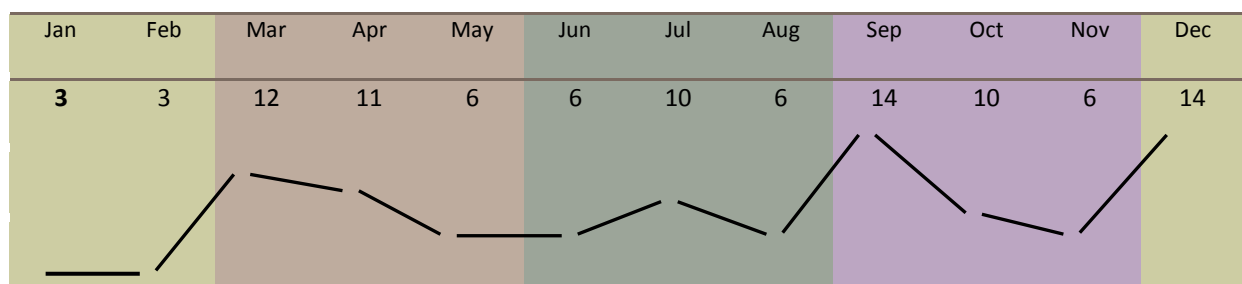
FIGURE 5: OBSERVED SEASONAL OCCURRENCE AND LIFE CYCLE OF PARALYSIS TICKS IN AUSTRALIA



It is also relevant to note the Paralysis Tick is not the only tick that can transmit *Borrelia*. Other tick species have been identified in other parts of the world and it is naive to assume the Australian Paralysis Tick is the only tick capable of transmitting *Borrelia*. Furthermore, there are any number of imported animals, including migratory birds capable of bringing infected ticks with them to Australian shores.

To determine potential seasonality risk of tick bite, participants who reported a tick bite were asked when they were bitten; 101 responses were recorded and are outlined in Figure 6, whose pattern is strikingly similar to the seasonal occurrence.

FIGURE 6: TICK BITE REPORTED BY SEASON



Diagnosing Lyme disease

Obtaining a diagnosis of Lyme disease is fraught with inconsistency in the Australian medical system. There has been no epidemiological study conducted in the Australian population, so the actual diagnosis of Lyme disease is also a controversial topic.

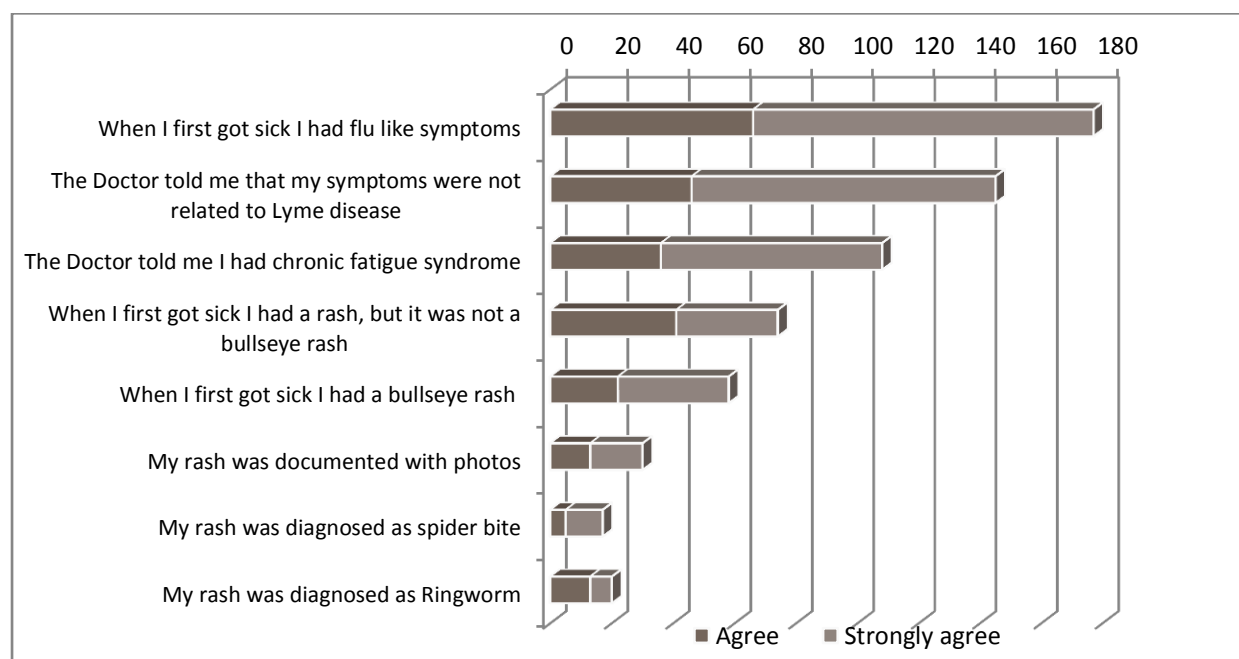
A hall mark practice in epidemiological studies is the aetiology (origin or causation) of disease, outbreak investigation and disease surveillance; each of which usually underpin a public health response. In Australia, we have none of these; the existence of Lyme disease is largely denied by Australian governments; there is dated research about competent vectors and hosts capable of transmitting Lyme disease; and as Lyme disease is not mandatorily notifiable there is no coordinated surveillance.

In fact, Australia is the only Organisation for Economic Co-operation and Development (OECD) country without a separate authority for national scientific leadership and coordination of communicable disease control and surveillance (Australia, Public Health Association of, April 2011). Therefore Australian clinicians are left to either educate themselves or refer to the *Factsheet on Lyme disease* and the *Lyme disease–testing advice for NSW clinicians* published by NSW Health which relies upon the clinical case definitions of Lyme borreliosis in Europe. What is clearly stated is that “Lyme disease is diagnosed based on symptoms, physical findings (e.g. a characteristic rash), and the possibility of exposure to infected ticks”.

Clinical symptoms & rashes

Our survey explored the symptoms of Australian patients with Lyme disease. In presenting a range of statements for ranking, respondents were able to provide a profile of symptoms associated with Lyme disease. Of significance was the presence of flu like symptoms with over 84% of participants reporting it at on set. These results are presented in Table 5: Common symptoms of Australian Lyme

TABLE 5: COMMON SYMPTOMS OF AUSTRALIAN LYME



In respect to rashes, it is commonly reported that most cases of Lyme disease commence with a rash known as Erythema Migrans (EM). Indeed in other countries doctors are advised that the presence of an EM provides clear clinical evidence to support the immediate diagnosis of Lyme disease. Our study examined the presence of a rash and asked participants to describe their rashes. All respondents answered this question; 50% reported they had a rash; 29% did not; and 21% don't remember. Results are reported in Figure 7.

In some cases the EM manifests as a bulls eye rash that features concentric red rings and in others the rash may be circular and red. Of the 113 (50%) respondents reporting a rash, we categorised the type of rash and report the results in Table 6.

FIGURE 7: PRESENCE OF A RASH IN AUSTRALIAN PATIENTS

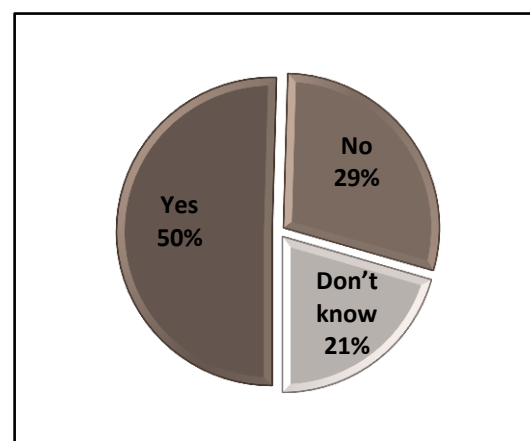


TABLE 6: REPORTED RASH TYPES

Type of rash	
Bullseye	31
Circular, red	38
Urticaria	2
Red, Lump	3
Red, welts	5
Red, blistered	3
Red, hot like sunburn	1
Red, itchy	4
Red, scaly	1
Red, spots	7
Rosacea	3
Scabies like	1
Shingles like	1
Similar to hives	1
Total	101

Diagnosis of Lyme disease and associated co-infections

Lyme disease can be accompanied by a variety of co-infections that may be transmitted during a tick bite. These co-infections include parasitic organisms like Babesia and Theileria; viral infections like Epstein Barr Virus (EBV), Parvovirus and Cytomegalovirus (CMV); and bacteria's like Bartonella, Rickettsia, Ehrlichia, Coxiella, Mycoplasma and others. Our survey sought to identify the common infections that Australian Lyme disease patients are diagnosed with.

Survey participants were asked to report if they had been diagnosed with Lyme disease and any of its common co-infections. A list was provided and participants could choose more than one response. A total of 220 participants answered the question; 87 (39.5%) respondents reported they have been diagnosed with Lyme disease only, no co-infections; 123 (55.9%) report they have one or more co-infections as indicated in Table 7; and 10 (4.5%) reported a co-infection only.

TABLE 7: LYME DISEASE & CO-INFECTION DIAGNOSIS

Diagnosis	Count		
Lyme disease (only)	87		
Lyme disease and co-infection	123		
Babesiosis		68	55%
Bartonella		63	51%
Chlamydia Pneumoniae		25	20%
Mycoplasma		35	28%
Ehrlichiosis		12	10%
Total	210		

In comparison with a 2010 patient survey conducted by the National Capital Lyme and Tick-borne Disease Association (NatCapLyme) in the United States, the Australian figures for co-infections are much higher than those reported in the United States. NatCapLyme found 46% of patients surveyed had two or more tick-borne infections. Babesiosis was most common and reported by 41% of patients and Bartonella was reported by 39% of patients.

It is well reported that Lyme disease patients who are co-infected with other tick-borne infections have a more prolonged and severe illness than those who are infected with Lyme disease only (Krause, 1996).

Other diagnosis

In addition to the co-infections of Lyme disease outlined in Table 7, respondents were asked if they had been diagnosed with any commonly reported conditions that can be caused by or result from chronic Lyme disease. As Lyme disease affects most systems in the body it has the potential to mimic other illnesses, like Multiple Sclerosis, or in fact contribute to some conditions, like Hashimoto's Thyroiditis and cause other symptoms like Chronic Fatigue Syndrome.

A list of common conditions was provided and respondents could select more than one condition. A total of 169 participants responded to this question and 58 (34.3%) reported only one additional condition. The remaining 111 (65.6%) of respondents reported more than one other diagnosis on top of their Lyme disease. Conditions and counts are outlined in Table 8.

TABLE 8: OTHER CONDITIONS REPORTED BY PATIENTS

Other conditions	
Attention Deficit Hyperactivity Disorder (ADD or ADHD)	11
Autism or Asperger Syndrome	6
Chronic Fatigue Syndrome (CFS)	128
Diabetes	8
Fibromyalgia (FM)	98
Hashimoto's Thyroiditis	18
Hormonal Imbalance	64
Migraines	80
Motor Neurone Disease (MND)	10
Multiple Sclerosis (MS)	22
Psychological disorder	72

In the same question respondents were provided an 'other' field to list any other conditions they had been formally diagnosed with. A total of 64 respondents provided additional conditions that ranged from Adrenal fatigue (3), Arthritis (19), Brucellosis, Depression (7), Epstein-Barr virus, HHV6, Malaria, Marshall's Syndrome, Morgellons disease, Parvovirus, Postural Orthostatic Tachycardia Syndrome (POTS), Q-Fever, Rickettsia (16), and Ross River Fever (5); the entire list reported extends to over 100 different conditions.

It remains to be proven as to whether Australian patients reporting other conditions, especially neurodegenerative diseases like Multiple Sclerosis (MS) for example, have been misdiagnosed, because their medical practitioners have not considered Lyme disease as a differential diagnosis. It should also be recognised that Lyme disease can be the cause of many other medical complications like Hashimoto's Thyroiditis due to its effect on the immune system.

Method of diagnosis

Participants were asked to report how they had been formally diagnosed with Lyme disease, either via a blood test, a clinical diagnosis based upon their symptoms or because they had a bulls eye rash. All participants answered this question; 192 (85.7%) of respondents reported a blood test formed all or part of their diagnosis; 8 (3.5%) were diagnosed on the basis of a bulls eye rash only; and 24 (10.7%) were diagnosed on the basis of their clinical symptoms as indicated in Table 9.

TABLE 9: METHOD OF DIAGNOSIS

Method of diagnosis	
Blood tests	35
Blood tests, Bulls eye rash	5
Blood tests, Clinical diagnosis (including symptom picture)	129
Blood tests, Clinical diagnosis (including symptom picture), Bulls eye rash	23
Bulls eye rash	8
Clinical diagnosis	2
Clinical diagnosis (including symptom picture)	18
Clinical diagnosis (including symptom picture), Bulls eye rash	4
Total	224

Length of time from bite to diagnosis

Where it was known, participants reported the year and month of their initial bite and also the year of their Lyme disease diagnosis. In correlating the data we have established the average number of years between tick, or other bite, and diagnosis of Lyme disease to be six and a half years as indicated in Table 10. This concludes that 80% of people acquiring Lyme disease in Australia will progress to the chronic stage.

TABLE 10: NUMBER OF YEARS FROM BITE TO DIAGNOSIS

Number of years	Years from bite to diagnosis	Average number of years from bite to diagnosis
0	23	
1	24	
2	6	
3	10	
4	7	
5- 10	22	
11 – 15	8	
16 - 20	7	
21 – 30	10	
31 or more	1	
Total	118	6.63 years

Lyme disease in local communities

To assist in determining the propensity of geographical clusters of Lyme disease, participants were asked if they knew of others in their local areas also diagnosed with Lyme disease. A total of 223 people answered the question, 125 (56%) reported they did and 98 (43.9%) reported they did not.

Number of doctors prior to diagnosis

General physicians in Australia lack knowledge about Lyme disease symptoms, diagnosis and testing, primarily because it is considered the domain of Infectious Diseases specialists. As such, patients presenting to general physicians are placed at risk of a delayed diagnosis and proper treatment. To determine the potential delays and impact upon patients, participants were asked to report how many Doctors or Specialists they had seen in Australia prior to obtaining a formal diagnosis of Lyme disease; 158 (57%) of patients report seeing more than 4 doctors; and 75 (33%) report seeing 10 or more as indicated in Table 11.

TABLE 11: NUMBER OF DOCTORS PRIOR TO DIAGNOSIS

How many Doctors/Specialists did you see in Australia prior to obtaining a diagnosis of Lyme disease?	
1	26
2 – 3	39
4 – 6	55
7 – 9	28
10 or more	75
Total	223

Testing for Lyme disease

Globally, laboratory diagnostic tests are recommended by the medical community if there are symptoms or clinical findings consistent with Lyme disease. However the type of tests used to determine whether a positive exposure to Lyme borreliosis has occurred is another area of controversy. To determine if a causative agent is present for infection, laboratory scientists use either 'direct detection' where they isolate the actual organism, or it's DNA, or 'serology' - the study of antibodies contained in blood serum.

Direct detection methods

According to strict scientific criteria, the direct detection, in culture, of an infectious organism (*Borrelia*) by polymerase chain reaction (PCR) or culture, is the only proof of a *Borrelia* infection. Detecting the DNA of *Borrelia* by PCR is also common, but much less sensitive and results may not confirm a positive presence. Because *Borrelia* can change its genomic DNA rapidly the efficiency of PCR detection can be decreased. Direct detection relies on the significant expertise of the interpreting analyst.

Serology

A blood test to determine whether antibodies to *Borrelia* infection are present in a patient's blood is the most common form applied in the diagnosis of Lyme disease. However there are limitations to this test process as *Borrelia* causes immune dis-regulation which decreases the specificity of antibodies. Often there is minimal, or no, measurable response (production of anti-bodies) by the immune system to a *Borrelia* infection. As such antibodies cannot be detected by ELISA tests (Hastey, 2012). Therefore many patients test negative and are not formally diagnosed with Lyme disease as a result. This means their disease could go untreated, possibly for many years, until they have developed chronic late stage Lyme disease.

Generally, testing follows a stepwise diagnostic process whereby a patient must test positive on an Enzyme-linked immunosorbent assay (ELISA) in order to proceed to a more sensitive 'confirmatory' immunoblot that looks for antigens - a Western Blot.

The issue with the stepwise diagnostic process employed in laboratories is that they are insufficiently evaluated for the detection of antibodies for *Borrelia* and so are not sensitive enough to serve as reliable, repeatable screening tools (ESCMID Study Group, 2004). The commercial ELISA products use recombinant antigens, in the presence of decreased antibody specificity and have high failure rates. There are also concerns about the quality of serological tests, the antigen preparations they rely upon and the choice of *Borrelia* strains used (Lange R, 2002).

There is considerable speculation that an Australian strain of *Borrelia* exists which has not yet been isolated for commercial testing purposes. As such, Australian patients are being tested for strains of *Borrelia* that they may not be infected with, hence a low rate of positive ELISA tests are likely.

Deriving their position from the CDC, NSW Health recommends clinicians follow the stepwise diagnostic process and advises that positive immunoassays will be automatically referred to one of two specialist laboratories at either Westmead or North Shore Hospitals for confirmatory immunoblot (NSW Ministry of Health, 2012). Patients wanting to order private immunoblot tests are being denied these services by the two specialist laboratories. This forces patients to send their blood overseas for testing in order to confirm their clinical diagnosis. The average cost of an overseas test for Lyme disease is around AUD\$1000. This places additional, and non-rebated expenses on Australian patients. To date there has been no acceptable explanation as to why patients and their physicians ordering immunoblot testing as a private service are being denied.

Testing outcomes

To gain a deeper understanding of the issues around testing in Australia, participants were asked a series of questions about the tests they have undergone as part of their Lyme disease diagnosis. We sought information on the type of blood test; the blood test results and information on the laboratory that performed their tests.

Respondents were asked if they had tested positive to Lyme disease through a blood test. Of those who reported having a blood test as part of their diagnosis for Lyme disease and who provided the result (182 respondents, 10 were blank), 121 (66.5%) reported their blood tests were positive for Lyme disease, 61 (33.5%) reported they were negative, as indicated in Table 12.

TABLE 12 : BLOOD TEST RESULTS

Have you tested positive to Lyme Disease through a blood test?	
Yes	121
No	61
Blank	10
Total	192

We further analysed test information provided by participants and note the most common tests used are the Western Blot and PCR's. Interestingly where ELISA tests are performed on their own, the rate of 'negative' result is higher than that of a positive result, but only marginally. From the information collected it was not possible to determine whether patients who reported their result actually underwent the step-wise diagnostic process involving an ELISA test followed by a Western Blot; test processes used are reported in Table 13.

TABLE 13: TYPES OF BLOOD TESTS USED TO SUPPORT DIAGNOSIS.

What types of blood test/s were used to support your diagnosis?	Result			
	Yes	No	Total	%
Type of test unknown	28	18	46	25.3%
Elisa only	3	4	7	3.8%
Elisa, PCR	1		1	.5%
Elisa, PCR, Western Blot	1		1	.5%
Elisa, Western Blot	6	2	8	4.4%
Elisa, Western Blot, Elispot		1	1	.5%
Elisa, Western Blot, PCR	3		3	1.6%
Elispot, Western Blot	1		1	.5%
PCR only	19	14	33	18.1%
Western Blot only	51	21	72	39.6%
Western Blot, PCR	8	1	9	4.9%
Total	121 66.5%	61 33.5%	182	

A number of respondents reported a range of other testing methods employed in diagnosing their Lyme disease, these ranged from measuring a patient's immune response with a CD57 lymphocyte count to Lumbar punctures and SPECT brain scans; a type of functional brain scan that can be used to determine physiological changes in the brain that may occur in Lyme disease.

Laboratory used for testing

According to the *Testing advice for Clinicians* (NSW Ministry of Health, 2012) laboratory tests should be conducted in National Association of Testing Authorities (NATA) accredited labs. In Australia the only accredited labs able to provide confirmatory immunoblot services for Lyme disease, that are NATA accredited, are the Institute for Clinical Pathology and Medical Research (ICPMR) at Westmead Hospital or the Pacific Laboratory Medicine Services (PaLMS) attached to the Royal North Shore Hospital. Outside of these two laboratories, who only progress to the more sensitive immunoblot when they receive a positive ELISA, patients are forced to use private testing services or to send their blood overseas for testing.

To highlight the testing dilemma Australian patients are faced with, we asked participants the name of the laboratory that conducted their tests. Of the 169 respondents answering the question, 102 (60%) of Australian patients have sent their blood to labs outside Australia. The ratio of negative vs. positive tests is higher in Australia as indicated in Table 14.

TABLE 14: LABORATORIES PERFORMING LYME DISEASE TESTING

Please tell us which lab and country provided your Lyme disease serological test/s?	Test result		
	Pos	Neg	Total
Australia			
Australian Biologics, Sydney, Australia	25	15	40
Hunter Pathology, NSW, Australia		1	1
Newcastle, NSW, Australia		1	1
Not sure	3		3
Pacific Laboratory Medicine Service (PALMS), North Sydney	6	1	7
Sonic Healthcare Group	5	5	10
University of Newcastle, NSW	1		1
Westmead Hospital, Sydney	2	2	4
Overseas			
BCA, Ausburg, Germany	2	2	4
Czech republic		1	1
IGeneX, Palo Alto, USA	68	27	95
Ireland		1	1
Western Florida Research Inc, Florida, USA	1		1
Total	113	56	169

Notes: Pos = Positive result on blood test; Neg = negative result on blood test.

A significant number of Australians are sending their blood to the United States laboratory, IGeneX¹, for testing. As outlined in Table 14, IGeneX are returning the highest ratio of positive tests, yet many Australian patients report that their IGeneX tests are not generally accepted in the Australian medical community. The implication is that IGeneX are not a NATA certified laboratory, as required by NSW Health, so Australian patients holding positive Lyme disease test results are often told the tests are not valid.

On the contrary IGeneX is a specialised Tick Born Disease reference laboratory, offering high complexity testing services that are certified and recognised by the American College of Pathologists, US Medicare and are Medicaid approved. IGeneX must submit to stringent quality standards and must also maintain licenses to perform patient testing from the states of California, New York, Maryland, Pennsylvania and Florida. These licensing processes are more stringent than the NATA accreditation process required for Australian labs.

¹ [Http://www.igenex.com](http://www.igenex.com)

Treatment

Like diagnosis and testing, the treatment of Lyme disease is also a debated area. There are two sets of opposing guidelines that are used for the treatment of Lyme disease emanating from the United States. One is the Infectious Disease Society of America's (IDSA) guidelines² who recommend a short course (no more than 30 days) of antibiotics for the treatment of Lyme disease and the other is the International Lyme and Associated Diseases Society (ILADS), evidence based guidelines³ who maintain that long term use of antibiotics is a more appropriate way to treat Lyme disease. A detailed Lyme Disease Guideline Comparison⁴ of the opposing treatment regimens is provided by ILADS on their website. Research about optimal treatments is often inconclusive, further undermining the validity of the treatment guidelines.

In their Lyme Disease Factsheet, NSW Health advises that "most cases of Lyme disease can be treated successfully with a few weeks of antibiotics" yet provides no evidence base to support the assertion. To test this assertion, our survey sought information from participants about their Lyme disease treatment, or lack of it. We asked about the type of treatment patients were undergoing, the effects of the treatment and the type of medical practitioner they were being treated by.

All respondents answered this question; 193 (86%) reported they were currently undergoing treatment for Lyme disease; 29 (12.9%) reported they were not and 2 respondents left the question blank but sought advice on how to locate a doctor who could treat them. Table 15 reports the result.

TABLE 15: PATIENTS CURRENTLY UNDERGOING TREATMENT

Are you currently undergoing treatment?	
Yes	193
No	29
Blank	2
Total	224

We examined the free text answers provided by many of the participants who reported they were not on treatment and concluded that a significant number of them are in the process of locating a suitable doctor to treat them for Lyme disease.

² [The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America](#)

³ [ILADS, Evidence-based guidelines for the management of Lyme disease](#)

⁴ [Lyme Disease Guideline Comparison: http://www.ilads.org/files/ILADS_Guidelines.pdf](http://www.ilads.org/files/ILADS_Guidelines.pdf)

Treatment regimes

Participants were asked to describe their treatment regimens and were provided with a list of common treatments. These included antibiotics, natural supplements, diet, adrenal treatment, hormone treatment, heavy metal chelation and salt and vitamin C combinations. Of the 193 people who reported they were currently undergoing treatment, they reported the various types of treatment they were using in Table 16.

TABLE 16: TREATMENT REGIMES

What does your treatment regimen include?	Count
Adrenal treatment	25
Antibiotics	137
Diet	122
Heavy metal chelation treatment	16
Hormone treatment	21
Natural supplements	147
Salt and Vitamin C combination	28

Participants were able to select a category for 'other' treatments they were currently undergoing. These additional treatments and therapies are outlined in Table 17.

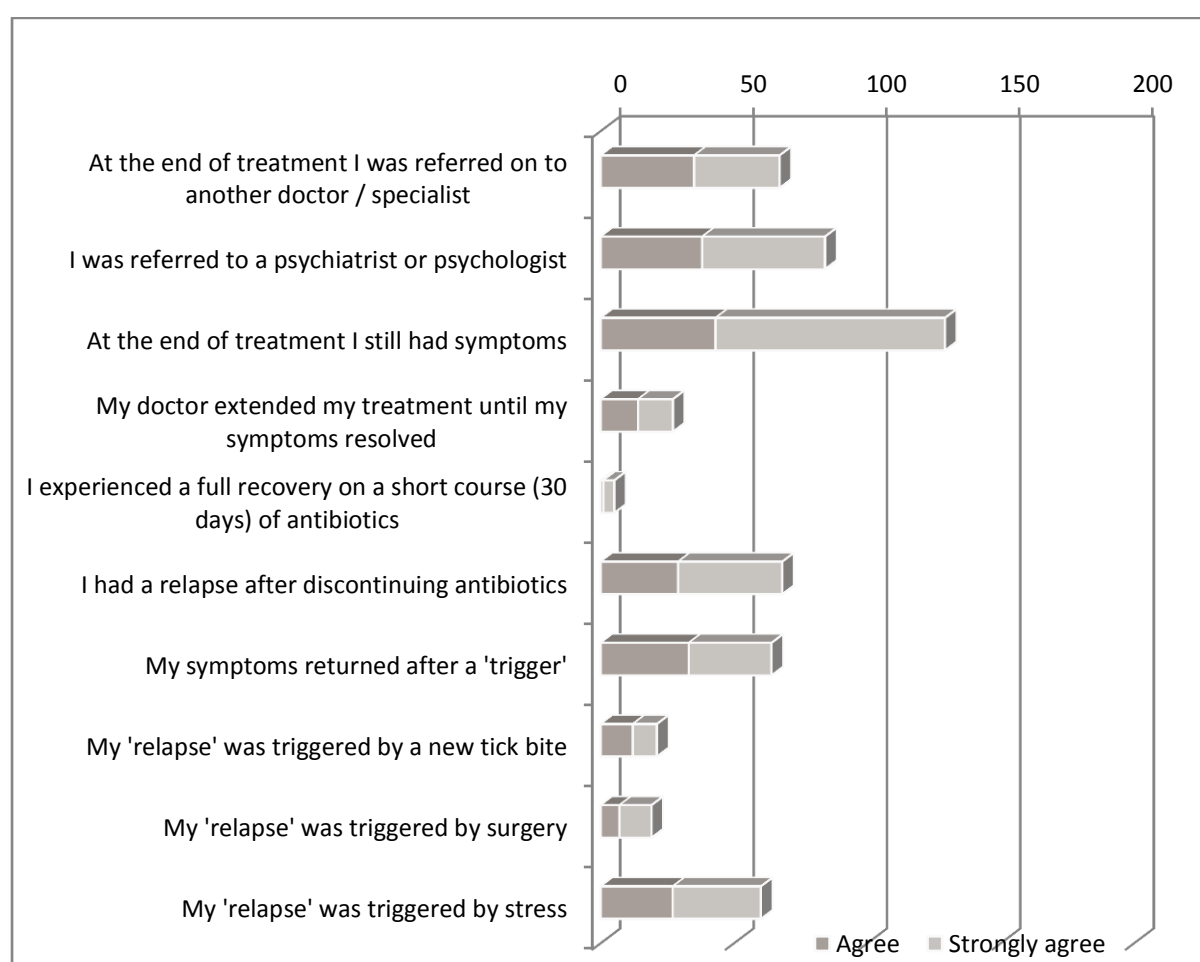
TABLE 17: OTHER TREATMENTS IN USE

Other treatments in use	Count
Anti-inflammatory drugs / food	1
Antivirals, anti-fungal lozenges	1
Anxiety medication	1
Bicillin Injections	1
Blood thinners	1
Colonics	1
Hyperbaric O2 therapy	1
Detoxification (FIR Sauna, Mud packs, Epsom Salt baths)	3
Exercise	3
Herbs / Herbal treatment	5
Holistic Dentistry	1
Homeopathy	2
IV Vitamin C + IV Glutathione	1
Lymphatic drainage massage	1
Marshall Protocol	1
Opiates	1
Osteopathy	1
Ozone / Oxygen Therapy	1
Physiotherapy / Chiropractic support	1
Probiotics	3
Rife	2
Traditional Chinese Medical (TCM)	1
Vitamin B / C/ D	5

Participants were also asked to rate their agreement, or not, to a number of statements about their treatment. Table 18: Treatment statements, provides responses from 212 participants who answered the question. It is interesting to note the majority of respondents symptoms remained at the end of their treatment; however the length of treatment of patients was not assessed as part of this survey, so these responses need to be interpreted with caution. Table 18

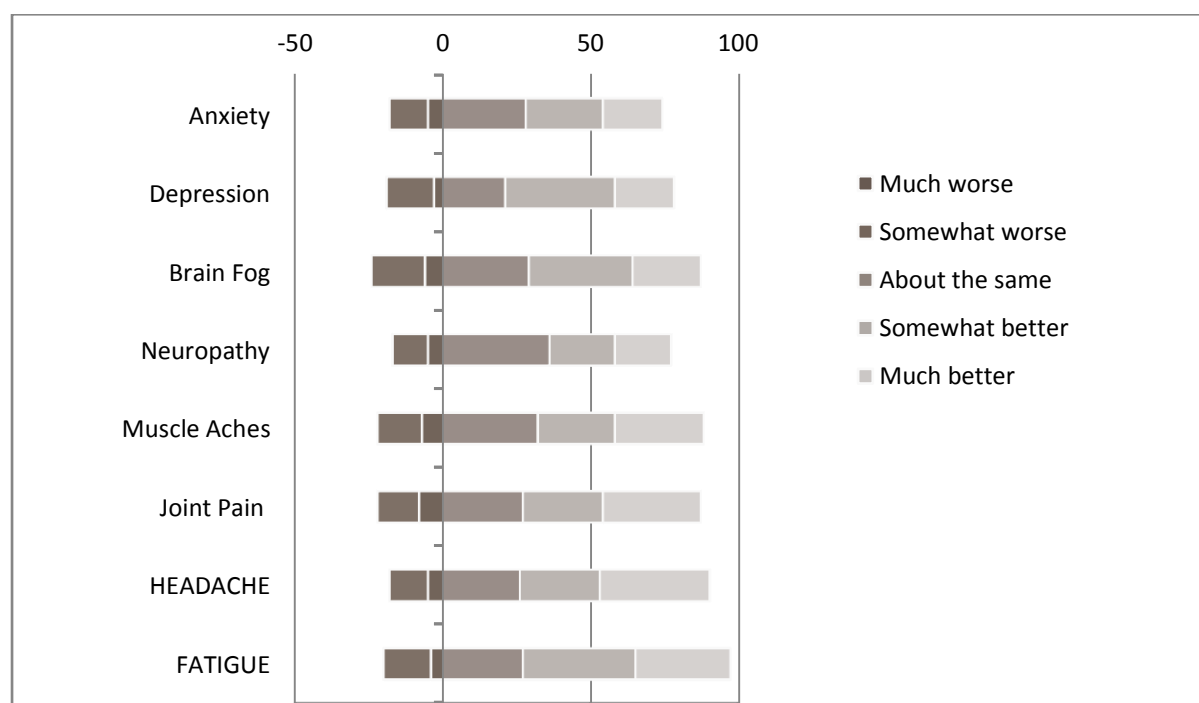
Furthermore, a number of respondents were referred on to other medical practitioners and just under half of those were referred to psychologists; the premise being that Lyme disease is 'all in your head'. Just over a quarter of respondents agreed that their Lyme disease symptoms were triggered by a new event, or relapsed after they concluded their antibiotics. A very minor portion of respondents report that they experienced a full recovery after 30 days on antibiotics; the majority did not.

TABLE 18: TREATMENT STATEMENTS



In assessing the effectiveness of the IDSA guidelines for treating Lyme disease, the survey addressed issues of treatment length it asked 'if 30 days antibiotic treatment was insufficient and required re-treatment, how has the additional treatment affected your health'. We provided a list of common symptoms that respondents were asked to rate whether those symptoms had improved, or remained the same; responses are outlined in Table 19.

TABLE 19: SYMPTOMS AFTER TREATMENT OF MORE THAN 30 DAYS ANTIBIOTICS



The majority of patients reported significant improvement with additional treatment; this provides some evidence that treatment under the IDSA guidelines, and those recommended by NSW Health is ineffective for Australian patients.

At the end of the treatment section respondents were able to offer additional information about their treatment; 167 respondents provided a commentary about their treatment. As most of the information was unique and too difficult to categorise, we developed a word cloud⁵ to help express some of the commonalities of patient experiences with their treatments.



⁵ A word cloud provides a visual representation of the most prominent words in a selected portion of text and presents those words in varying sizes according to their frequency of use.

Lyme disease & Australian medical practitioners

The Australian medical community has little, if any, knowledge of Lyme disease and how to diagnose and treat it. This is largely because zoonotic diseases fall under the domain of Infectious Disease specialists; the disease itself is difficult to diagnose, especially if the patient does not have a tell-tale bulls eye rash, as the many varied symptoms can mimic so many other diseases. Added to these complications, is the geographical location of Australia being outside reported endemic areas for Lyme disease; and the long term denial by NSW Health that Lyme disease does not exist here.

Collectively, these issues mean that general practitioners do not receive basic education about Lyme disease or tick borne illnesses, and those who may suspect a case of Lyme like illness refer to the only official health advice; the *NSW Health factsheet – Lyme Disease* or the *Lyme disease testing advice for NSW Clinicians* (NSW Ministry of Health, 2012).

For Australian patients, the consequence of the wide lack of medical practitioner education means that most will go undiagnosed for more than 6.6 years on average, as outlined in Table 10. The impact is that 80% of Australian patients, infected with *Borrelia*, will progress to chronic Lyme disease before they are even diagnosed.

Australian patients have a dismal story to tell in respect to being diagnosed and treated for Lyme disease. Our survey asked participants for information on the types and number of medical practitioners they had seen in their Lyme disease journey and the location of the physicians treating them.

Number of medical practitioners seen prior to treatment

In terms of obtaining a diagnosis and being treated, very few patients (39 or 18%) reported seeing only one doctor. The majority had seen more than 2 doctors and 128 (60%) had seen more than 4 doctors; results are indicated in Table 20. In addition, 156 (75%) respondents reported it was difficult to find a doctor who would treat them for Lyme disease.

However this situation is not unique to Australia. In 2009 the California Lyme Disease Association (CALDA) conducted a similar survey and found that 35% of patients consulted 10 or more doctors before receiving a diagnosis of Lyme disease (California Lyme Disease Association, 2009).

TABLE 20: NUMBER OF DOCTORS SEEN PRIOR TO TREATMENT

How many doctors/specialists did you see in Australia prior to being treated specifically for Lyme disease?		
1	39	18%
2 – 3	46	22%
4 – 6	40	19%
7 – 9	27	13%
10 or more	61	29%
Total	213	

Type of physicians treating Lyme disease

Participants reported the type of physician that is currently treating them for Lyme disease. Of the 194 respondents, 84 (43.2%) were currently being treated by one type of doctor; either a general practitioner (GP), Lyme Literate Medical Doctor (LLMD), Naturopath, or Rheumatologist; and the remaining 110 (56.8%) report being treated by one or more types of physicians. Respondents could select more than one type of treating doctor; results are reported in Table 21.

It should be noted that the majority of LLMD's in Australia are in GP's with an interest in Lyme disease; they may have completed specific Lyme disease training with ILAD's however as at of July 2012 they lack the significant patient experience held by their overseas counterparts.

TABLE 21: TYPE OF TREATING PHYSICIAN

What type of physician are you currently being treated by?	
GP	121
Infectious disease specialist	4
LLMD	135
Naturopath	58
Rheumatologist	11

Other physicians and therapists treating Lyme disease

Due to the wide range of symptoms reported in Lyme disease, many respondents told us they were also being treated by a range of other specialist physicians or therapists, these included Acupuncturists, Cardiologists, Dermatologist, Homeopath, Neurologists, Osteopaths and Traditional Chinese Medicine practitioners.

Access to doctors treating Lyme disease

To further determine access to medical practitioners treating Lyme disease, our survey asked participants whether their current physician was from Australia; 155 (74.5%) of respondents told us their primary physician treating Lyme disease is located in Australia, 53 (25.5%) reported their primary treating physician is outside Australia.

Distance patients are travelling for their Lyme disease treatment

The survey asked participants to report the greatest distance they had travelled to obtain treatment for Lyme disease; 101 (48%) of respondents were travelling distances of more than 100km; with 48 (23%) travelling over 500km and 19 (9%) report they had travelled overseas for treatment, as reported in Table 22. Using the mid-point of each listed distance, we calculated the average distance Australian Lyme disease patients are travelling to be 236km.

TABLE 22: GREATEST DISTANCE TRAVELLED FOR LYME TREATMENT

What is the greatest distance you have travelled for treatment of your Lyme disease?		
< 50km	61	29%
50 - 100 km	29	14%
100 - 500 km	53	25%
> 500 km	48	23%
Overseas	19	9%
Total	210	100%

Overseas countries for treatment

Of 19 respondents who reported they had travelled overseas for treatment, the countries they attended for treatment are reported in Table 23; 3 respondents did not state the country they travelled to.

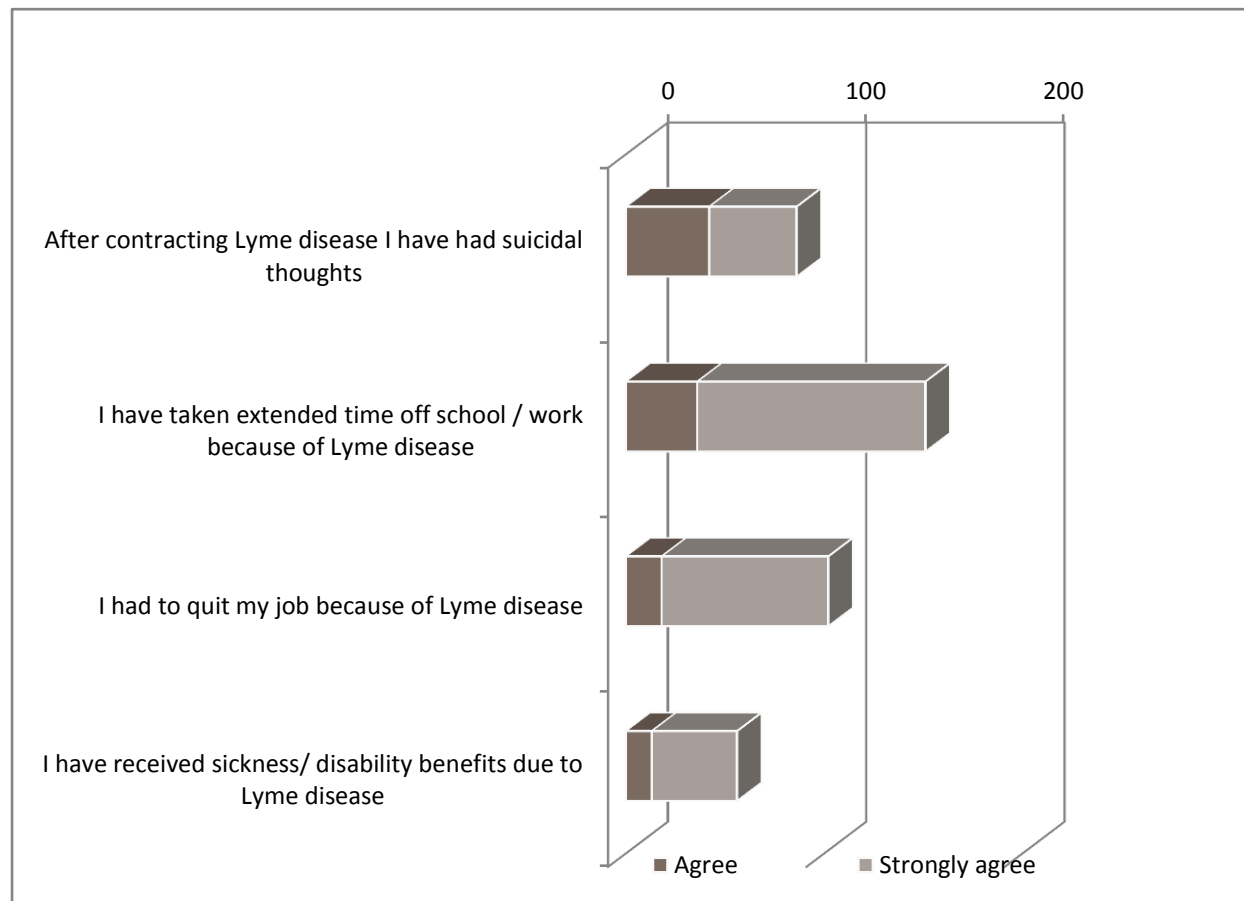
TABLE 23: COUNTRY OF TREATMENT

Which country did you travel?	
United Kingdom	2
United States	9
Germany	3
Indonesia	1
Thailand	1
Total	16

Patient impacts

To help profile the impact upon Australian Lyme patients we presented a series of statements about the effect that Lyme disease has had on patient lives and respondents were asked to rate them. Respondents told us they had social, financial and psychological impacts through having Lyme disease, these are outlined in Table 24.

TABLE 24: IMPACT STATEMENTS



Many respondents offered their personal stories in the free text fields of the survey. Sadly the themes were common and revolved around the personal consequences of living with Lyme disease, from the significant decline in the quality of life, the deficits in functionality, the dwindling social connections and the increasing social isolation exacerbated by having a long term illness where recognition and education is almost non-existent.

A number of patients shared their financial distress and reported having to give up their work due to declining cognitive function which in turn impacts upon their ability to afford health care and ongoing treatment. Many of these costs might have been avoided if patients were tested appropriately, diagnosed promptly and treated accordingly for Lyme disease, before it became chronic.

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Images

Figure 1: *Borrelia burgdorferi* -spirochete Figure 1: *Borrelia burgdorferi* -spirocheteaccessed from
<http://lymediseaseguide.org/lyme-disease-pathology> 26 September2012.

Figure 5: Observed seasonal occurrence and life cycle of paralysis ticks in Australia, accessed from
<http://www.animaloptions.com.au/index.php?page=paralysis-ticks> adapted from (Clunies-Ross, 1935).