Karl McManus Foundation ::
September **::** *National Lyme Disease Appeal*

LYME DIS— EASE

Lyme Facts
:: for ::
Pharmacy Staff

The Facts in Australia ::

WHAT PHARMACY STAFF NEED TO KNOW ABOUT LYME DISEASE IN AUSTRALIA

KARL MCMANUS FOUNDATION

What is Lyme disease?

Lyme disease, also known as Lyme borreliosis, is an infectious disease transmitted by ticks or other insects. The bacteria that causes Lyme disease comes from a group called *Borrelia burgdorferi sensu lato*. There are at least twenty species known to infect humans that can cause disease. They are part of the spirochete family like syphilis (*Treponema pallidum)*.

Lyme disease was first diagnosed in children presenting with arthritic symptoms in Lyme, Connecticut USA in 1975. In early disease (stage 1) the bacteria is localised to the bite site. Within weeks the bacteria can spread/disseminate into various tissues (stage 2). If not treated early, a chronic systemic infection may develop (stage 3).

Diagnosis

Not all Australian ticks are infected with Lyme bacteria. There is no diagnostic test that is totally reliable in detecting Lyme disease. Negative test results DO NOT necessarily mean it is absent. Australian testing is inadequate. Reliable Lyme blood tests are best obtained in laboratories in the USA or Germany. Diagnosis can be made on clinical grounds. To find a list of recommended laboratories world-wide, please visit the Karl McManus Foundation website.

Characteristics of Borrelia

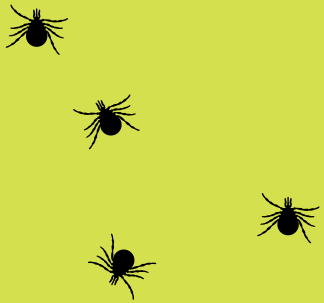
— A spirochete (spiral-shaped bacteria) that also exists in atypical forms such as cell wall deficient and cyst which can lay dormant for years *(Miklossy, 2008)*.
— A slow replicating bacteria, hence a slow onset of symptoms. Prolonged antibiotic treatment is usually required.
— It is immunosuppressive, immune evasive, produces toxins and forms biofilm.
— Contains 21 plasmids which confer a high degree of genetic variation.
— Multiple geno-species which gives rise to variations in virulence and differences in symptomatology.
— Transmitted in utero and sexually.
— During antibiotic treatment, symptoms can worsen due to rapid toxin release (see Herxheimer reaction on page 9).

These characteristics can complicate clinical diagnosis, diagnostic evaluation and treatment protocols.

INFECTIOUS DISEASE

UNRELIABLE TESTING

SPIROCHETE BACTERIA



SKIN RASH

MUSCLE TWITCHES

FACIAL PARALYSIS

The 'great imitator'

Lyme disease is a great imitator as its symptoms overlap with many other conditions leading to misdiagnosis. In Australia they include motor neurone disease (MND)/amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Parkinson's disease, Alzheimer's disease, myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS), autism, fibromyalgia and arthritis.

Until appropriate, reliable diagnostic tests for the Australian species of Lyme bacteria are developed, many patients will continue to be misdiagnosed with the above conditions.

What are the symptoms and signs?

Symptoms appear within days, weeks or months following a tick bite. Different areas of the body are affected in varying degrees and symptoms come and go. They may include:

General: fever, sweat attacks, prolonged tiredness, sore throat, stiff neck, muscle and joint pain. Unexplained weight gain or weight loss.

Neurological/musculoskeletal: muscle twitches, tingling, numbness, light and noise sensitivity, headache, dizziness, Bell's palsy (facial paralysis), difficulty swallowing, muscle weakness, gait (walking style) problems, speech difficulties, tremors and unexplained joint swelling and pain.

Dermatological: a bullseye rash (erythema migrans) at the bite site or other parts of the body. A generalised rash all over the body may occur. Not all patients get a rash. A skin condition called acrodermatitis chronica atrophicans (ACA).

Psychological: confusion, difficulty thinking and concentrating, forgetfulness, poor short-term memory, disorientation, dyslexia, depression, paranoia, panic attacks, anxiety, hallucinations.

Gastrointestinal: nausea, vomiting, constipation, diarrhoea and upset stomach, pain or heartburn.

Genito-urinary: irritable bladder or interstitial cystitis, testicular or pelvic pain, decreased libido, unexplained menstrual irregularity and unexplained milk production.

Respiratory & cardiovascular: shortness of breath, cough, endocarditis, myocarditis, heart failure, chest pain or rib soreness, peripheral vascular abnormalities and rhythm disturbances—extra beats, heart block, palpitations.

Information about ticks

Ticks feed only on blood and are described as 'nature's dirty needles'.

Ticks inject a local anaesthetic at the bite site and you may not be aware of being bitten. In addition, the larvae and nymphs are so small (1-3 mm) they are difficult to detect.

The most common species associated with bites is the paralysis tick *(Ixodes holocyclus)*. Other species include the bush tick *(Haemaphysalis longicornis)* and brown dog tick *(Rhipicephalus sanguineus)* (see page 7). Ticks have eight legs in the nymph and adult stages (six as larvae) and are related to spiders and mites. Larvae are often called grass ticks, and nymphs are often called seed ticks. The paralysis ticks are known as three host ticks as they require three feeds to complete their life cycle between stages larvae-nymph-adult.

Do Australian ticks carry the Lyme disease bacteria?

A study identified Borrelia spirochetes in paralysis ticks as well as bush ticks *(Wills & Barry, 1991)*. Another study found spirochete-like objects in Australian ticks but could not identify them as Borrelia *(Russell et al., 1994)*.

Further scientific evaluation is required to ascertain which tick species carry the Lyme disease-causing bacteria in Australia.

Can Lyme disease be prevented?

You can protect yourself from Lyme disease by being aware of the risk that ticks present and using simple measures to avoid being bitten. For tips on how to stay tick free see page 6.

Images: (*Opposite page*)
A Red blood cell. **B** Borrelia spirochete: extracellular. **C** Borrelia cyst: extracellular. **D** Babesia: intracellular. **E** Babesia: tetrad. **F** Maturing Babesia: lysing the red blood cell. **G** White blood cell: monocyte. **H** Ehrlichia infected monocyte. **I** Bartonella.

NATURE'S DIRTY NEEDLES

LYME DISEASE PREVENTION

REMOVE TICK ASAP

How to remove a tick

1. It is important to remove the tick as soon as possible.
2. Use a specifically designed tick remover or fine-point tweezers.
3. It is important to grasp the tick at its mouth parts, as close to the skin as possible.
4. Pull the tick upwards with steady pressure (resistance at the point of attachment is common).
5. DO NOT squeeze the tick body as this increases the chance of pathogen transmission.
6. DO NOT try to kill the tick with methylated spirits, petroleum jelly, kerosene or any other chemicals as this could cause the tick to inject more toxins and pathogens.
7. Wash the bite area and hands thoroughly.
8. For removal of larvae, soak in a bath with 1 cup of bicarbonate soda added for 30 minutes or use benzyl benzoate lotion after a hot bath. 24 hours later have another hot bath.
9. Save the tick in a sealed jar with a leaf or blade of grass and label with the date and the locality where the tick was acquired. The tick can be identified later if you develop illness, especially in the following four weeks.
10. If you notice any symptoms seek medical advice promptly.

ADDRESS CO-INFECTIONS

ANTIBIOTIC TREATMENT

DETOXING & PROBIOTICS

Co-infections

Ticks transmit not only Borrelia bacteria but also other infections such as Babesia, Bartonella, Anaplasma, Ehrlichia, Rickettsia, Mycoplasma and viral pathogens.

The symptoms of these other infections closely resemble that of Borrelia. This further complicates the diagnosis and treatment of Lyme disease. A guideline to the treatment of co-infections is outlined in Table 1 in "Lyme Facts for Pharmacists".

Treatment

Many Australian doctors are not familiar with treating Lyme disease and there is an urgent need to provide training. If affected, see a doctor who is aware of Lyme disease.

Lyme disease is treated with antibiotics. The earlier the antibiotics are started, the better the outcome. Borrelia bacteria can exist in three different forms (spirochete, cell wall deficient and cyst), hence it is critical the antibiotic treatment should address all three forms (see Table 1 in "Lyme Facts for Pharmacists").

Optimum duration of treatment depends on the severity of symptoms and the combination of co-infections that is delivered via the tick bite.

Preventative prophylaxis after a tick bite, requires four weeks of treatment with doxycycline 100mg twice a day for adults and clarithromycin twice a day for children.

If the treatment is started three months post tick bite, when Borrelia infections are considered as chronic, then three different antibiotics should be administered to address the three different forms of Borrelia. For more detailed treatment guidelines please refer to "Lyme Facts for Pharmacists".

Herxheimer (die-off) reaction is very important in Lyme disease treatment.

During antibiotic treatment, endotoxins are released from dying Borrelia and accumulate, causing the patient's symptoms to worsen. This is also known as the Jarisch-Herxheimer reaction. Minimising a Herxheimer reaction by fine-tuning antibiotic therapy is vital. The toxins released are both lipophilic and hydrophilic, the lipophilic toxins being harder to remove.

The lymph is an important organ in toxin elimination and supporting the lymph system is essential. The detoxing process can be aided by other pharmacotherapies as listed in "Lyme Facts for Pharmacists".

Images: (*Opposite Page*)
A Nerve cell. **B** Borrelia spirochete: extracellular. **C** Borrelia spirochete: intracellular. **D** Borrelia cyst: extracellular. **E** Borrelia cyst: intracellular. **F** Borrelia cell wall deficient: intracellular. **G** Babesia: tetrad. **H** Bartonella.

Karl McManus' story

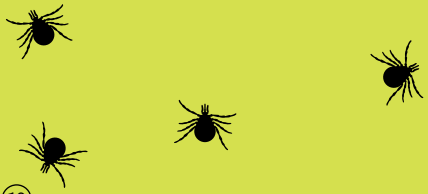
Karl McManus was bitten by a tick in July 2007 on Sydney's Northern Beaches. A week later he developed flu-like symptoms, but due to a lack of knowledge about Lyme disease in Australia, the tell-tale signs and potential seriousness of the tick bite were overlooked.

Five weeks later Karl experienced more of the classic symptoms of Lyme disease. He began to lose dexterity in the fingers of his left hand accompanied with muscle wasting. In November 2007 Karl was misdiagnosed with multi-focal motor neuropathy (MFMN) and given an immuno-suppressive agent which worsened his condition. As a result the treatment was stopped.

It was not until April 2008, when his blood was sent to a US laboratory and his tests came back positive for Lyme-disease bacteria, that Lyme disease was confirmed. However, Karl was unable to find a doctor in Australia who was aware of or could treat his neuroborreliosis. Without proper monitoring he continued to deteriorate.

Karl passed away suddenly on 14th July 2010. His decline and death was due to a refusal by the medical system to accept he had Lyme disease and treat him accordingly.

Karl McManus did not want anybody to suffer like him ever again…



AUSTRALIAN FAMILIES

AUSTRALIAN SPECIES

MISDIAGNOSIS THREAT

Karin's story

In September 2008 I got a tick in the head in Mapleton, SE QLD. It was removed by my GP, but had been there 2-3 days. Two weeks later I became ill with brain fog, extreme tiredness, dizziness, loss of appetite, gastric upset and generally felt very unwell. The GP prescribed Flagyl for giardia. My symptoms abated slightly for a few days, then quickly returned and worsened.

Since becoming ill, I have had many tests. My GP couldn't figure out what was wrong with me. In desperation I searched the internet and learned about this disease called Lyme. I sent my blood to the US for testing and that testing came back positive.

I currently am taking some alternative treatments. My GP empathises but really has no idea what to do with me. I am usually housebound, often resting in bed, unable to work, unable to drive. I'm really at my wits end.

— Karin, Sydney

RAISING AWARENESS

FACILITATING RESEARCH

REMOVING BARRIERS

Gundy's story

My husband and I have both got Lyme. We are both now on treatment (which is working), thanks to a doctor who believes that Lyme disease exists in Australia.

We have been suffering since 2007. We've been to so many different doctors and specialists and no-one could tell us what was wrong.

I knew that whatever was wrong with me was caused from the tick because all these stupid symptoms which would come and go – from being not too bad to not being able to lift my head off the pillow – all started about two weeks after I was bitten by three ticks.

— Gundy, Australia

About the foundation

The goal of the Karl McManus Foundation is to remove the barriers to the recognition and treatment of Lyme borreliosis, especially neuroborreliosis, in Australia and to contribute to knowledge in the world about borreliosis and other tick-borne infections.

The aims of the Foundation include:
1. To facilitate research and raise awareness of Lyme borreliosis, co-infections and other tick-borne diseases in Australia.
2. Advocate for better testing and treatment.
3. Educate doctors and other allied health professionals.
4. Use the media to alert the public about Lyme disease and co-infections in Australia.
5. Publicise that there is a potential to misdiagnose Lyme disease as many other serious chronic diseases including motor neurone disease (MND) /amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Parkinson's disease, Alzheimer's disease, myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS), autism, fibromyalgia and arthritis.

Your Donation

The goal of the Karl McManus Foundation is to raise $1 million for Lyme disease research and prevention in Australia. This will involve opening The Lyme Disease Research Centre at the University of Sydney and educating Australian doctors in the diagnosis and treatment of Lyme disease.

Your donation is very much appreciated.

This leaflet can be downloaded from the Karl McManus Foundation website where you can find out more about Lyme disease, including links to many other resources — www.karlmcmanusfoundation.org.au

Recognising. Understanding. Caring.

Thanks for
:: your ::
time & support

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Please don't throw this leaflet away. Pass it on to spread awareness of Lyme disease.