

As a patient, it is your right to have control over the type of testing and treatment you receive from your doctor. Insistence may be key in obtaining proper diagnostic tools from your physician.

If the Lyme infection is recent, your doctor will be able to order serology tests (blood work) specific for Lyme. The test used in Canada is called the ELISA, which stands for enzyme-linked immunosorbent assay; it is sometimes also called the EIA (enzyme immunoassay). Although this test is known to be notoriously inadequate, current protocol dictates to physicians that *only if* the ELISA is positive can a Western Blot be performed for further Lyme consideration. A Lyme literate doctor knows that reliance on the ELISA result is not enough, and therefore extra lab tests are usually ordered from a Lyme laboratory in the United States, an expense to the Canadian patient.

Herein lies a second issue. Rumour exists among health professionals that these lab results cannot be recognized as the labs are not certified. This is not true. The IGeneX labs used for these studies have been in practice for years and hold state licenses as required. Proof of certification is available through our office.

If this portion of your diagnosis with your family physician is obtained, you are on the way to receiving proper treatment. Your test results (*both* the ELISA and the Western Blot) along with your physician's *clinical* diagnosis will confirm or deny your need for treatment of Lyme. A positive Lyme diagnosis will then result in oral antibiotics being administered for up to 30 days.

However, if the results of your IGeneX tests indicate chronic Lyme, then long-term antibiotic treatment will likely be necessary to eradicate the intra-cellular bacterium. This creates a third issue, as the protocol for Lyme treatment states that 30 days of antibiotics is sufficient. Your doctor may or may not be willing to treat past this 30-day mark.

Other options for treatment must be considered at this point. This includes out-of-country treatment at full

expense to the patient. The Society can assist you with further information to help you through this difficult hurdle.

If your doctor is willing to treat you with long-term therapy, antibiotics are then administered orally or through intramuscular injections for periods of months or even years. Intravenous antibiotics can only be ordered by Infectious Disease doctors. This may pose a fourth issue in obtaining treatment as there is doubt among this branch of the medical profession as to whether "chronic Lyme" actually exists and therefore they become unwilling to treat or even test further for Lyme.

What are some side effects of treatment?

Chronic Lyme patients often have a severe reaction during treatment known as a Jarisch-Herxheimer reaction. This is normal and is caused by the build-up of toxins created when large quantities of spirochete bacterium are killed off by the antibiotics. This results in a severe spike in symptoms. Most patients will say they feel markedly "worse" during this period. Some patients have such severe reactions their therapy is halted out of fear. Depending on the severity of infection, this Herxheimer reaction may last longer in some than in others. The severity of the reaction can also lend itself to necessary adjustments in the type of antibiotics being used. Usually these adjustments make this phase more bearable for the sufferer to continue treatment.

Lyme is an insidious and debilitating disease. It has reached epidemic proportions across the world and has the highest rate of misdiagnosis globally. It is our mission to educate and further research Lyme to effectuate positive changes within our health care system for victims of Lyme in Canada.

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What is Lyme disease?

Lyme disease is an infectious disease carried by various birds, rodents, deer and ticks. There is indication that mosquitos and other biting insects may also be vectors to this disease (able to spread it by biting new hosts). It is passed among the animals and insects in this group when a tick latches onto an infected host, usually a Deer mouse.

The bacterium in the infected blood of the mouse enters the stomach of the tick as it feeds off its new host. This bacterium is a cork-screw shaped organism called a spirochete. The particular spirochete responsible for Lyme disease is *Borrelia burgdorferi* (*Bb*).

The disease was first discovered in 1970 when the characteristic bull's-eye rash appeared on some men from the Groton, Connecticut submarine base. Studies of reported findings by Navy doctors in 1974 also showed incidence of Lyme.

The disease became further well known after it affected a large group of families in the town of Old Lyme, Connecticut, where the current name of Lyme disease was coined.

Where is Lyme disease found?

Lyme disease is found in stomachs of ticks across the globe. Various species of ticks exist worldwide, but the North American species responsible for infections are the *Ixodes pacificus*, *Ixodes angustus* and *Ixodes scapularis*.

Lyme disease is the fastest growing infectious disease in North America, according to the Centers for Disease Control (CDC) reporting in 2006. The rate of increase has been tenfold annually, although the CDC is only reporting between 4-6 cases in every province in Canada.

Why? A positive Lyme diagnosis is only reported to the CDC when a patient tests positive on both an ELISA and a Western Blot; two testing methods being used in Canada that offer notoriously false results. There is also a very high

degree of missed diagnoses from a large portion of physicians outside of the Lyme literate medical community.

What are the symptoms of Lyme?

Lyme disease is characterized by a bull's-eye rash that often develops around the site of a known tick bite during initial infection. It has been discovered that this rash or bull's-eye formation only appears in 30% of the bite sites.

After skin penetration, the *B. burgdorferi* bacterium moves throughout the area between cells in the skin by "hitching a ride" with other cellular components and interacting with cellular bodies. This movement is indicated by expansion of a visible rash in an outward spread. It then disseminates from the skin cells to other cells in organs rather quickly. Along the way, it replicates and destroys, leaving behind a trail of dead host cells, penetrating and emerging through these cell's membranes. Within days to weeks after initial infection, *Borrelia* can be found in the blood, cerebro-spinal fluid, tissue surrounding the heart, the retina of the eye, muscle tissue, bone, the thin layer of membrane surrounding the brain, the brain cells, the spleen and liver.

The rapid invasion of multiple organs leads to a myriad of symptoms that are very often considered symptoms of other diseases such as Chronic Fatigue, Arthritis, Fibromyalgia, Parkinson's, Alzheimer's, Lupus, MS, ALS and much more.

Lyme is known within the medical community as the "Master Mimic" due to the presence of multiple copy-cat symptoms of other diseases, thus leading to the high rate of misdiagnosis. This misdiagnosis leads to Chronic Lyme, a much more invasive stage to eradicate. A full checklist of symptoms is available through our office.

What can I do if I suspect I have Lyme?

If you have had or just recently suffered a known tick bite, or were exposed to a tick area (camping, gardening,

walking in tall grass) at any time prior to an onset of symptoms, Lyme must be considered by your family physician.

If you were at any time in an area known for the presence of ticks (wooded areas, gardens, grassy areas, your own back yard) and you have been diagnosed with another disease in which treatment therapies are failing, you may also be a victim of Lyme.

It is stated by the medical protocols surrounding the treatment of Lyme that the diagnosis for Lyme must a "clinical diagnosis" as the available testing methods are known to not substantiate truthful results on their own. If the infection for Lyme is recent (acute), it can be treated with a simple round of antibiotic therapy. If the infection has been able to progress through the body over time (chronic), a long-term antibiotic treatment therapy may be required. Some doctors even believe that Lyme simply does not exist in various areas of the country.

Many doctors do not know the facts about Lyme and so may be less willing to cooperate in proper treatment, especially regarding long-term antibiotic therapy. For these situations, the **Physician's Corner** section of the Society's website outlines the protocol, testing methods, clinical diagnostic tools and current research results of top Lyme literate doctors across the globe. Accessible only to medical professionals, the **Physician's Corner** is packed full of valuable information to help educate and assist physicians in the treatment of Lyme in their practices.

If need be, Dr. Murakami makes himself available to discuss Lyme with inquiring physicians. Your doctor can contact Dr. Murakami through our office.

What can I expect for treatment of Lyme?

Although protocols do exist to help physicians in the diagnosis and treatment of Lyme, proper research and education are severely lacking, leaving these protocols outdated and seriously limited in options for physicians.