Ticking off Lyme
a guide to having fun outdoors for a very long time!

Sarah Hutchison
Introduction

When I moved to the mountains from the city in 1995, it was well-known to check for ticks in the springtime after a day out of the mountains, because they could carry Rocky Mountain Fever. No one was very concerned about Lyme disease – we were taught that it didn’t exist in Alberta. That story is now changing. Lyme disease, a debilitating illness spread by ticks, is on the rise worldwide.

Since Lyme disease is easily treatable if caught within days of the tick bite, and later stage cases are more likely to become long term and complex to treat, early identification is key. But Lyme is not yet on the radar of all physicians in Canada and Canadian lab testing is unreliable, so early cases are frequently missed.

This book is one of many initiatives aimed at changing this situation and keeping Canadians healthy while they enjoy the outdoors!
Bugger: lyme is in Alberta

Dr. James Talbot, chief medical officer for Alberta Health, said that in 2013 veterinarians submitted 960 ticks found on pets and livestock in Alberta for testing. Of those, 139 were adult blacklegged ticks, the main carriers of Lyme. One in five of the blacklegged ticks tested positive for B. burgdorferi, the bacteria that causes Lyme.

2013 Surveillance Study, Alberta

- 960 ticks
  - 130 black legged ticks (carriers)
  - 1/5 positive for Lyme

Ticks can be found in rural, urban and grassy or woodland areas.

Lyme is on the rise worldwide. The number of reported cases is estimated to move from 500 to 10,000 a year in Canada by the year 2020. And this is not accounting for the unreported cases which are significant at this point because of medical controversy.

Surveillance studies have established that Lyme can be present in Alberta ticks. Alberta Health states that the risk is low, but if you look at the data closely, in the areas where a large number of Lyme carrying tick species were submitted, a sizable percentage carry Lyme. 67% of ixode ticks submitted from the Edmonton area carried Lyme, also suggesting that Lyme disease has moved beyond just the Canadian border as some reports state. Lyme can be anywhere that animals and migratory birds move through, including cities. This makes identifying the exact areas in Alberta where the risk is highest very difficult, and the concentrated areas where Lyme was found a concern to all.

2014 Surveillance Study, Alberta:

**Lyme habitat**

You are most likely to encounter ticks, the main carrier of Lyme disease, in brushy, overgrown grassy, and wooded habitats, including green spaces in cities (you can reduce tick, deer, and rodent habitat by removing leaves, tall grass, and brush from areas surrounding work areas or residential areas). Ticks are most active in the spring and early summer. They can be active in winter when temperatures are above 4 degrees Celsius. Late summer often is too hot and dry for ticks to survive.

If you are travelling, most public health sites have local information about Lyme and ticks. However, statistics are not keeping pace with the spread of Lyme so it's best to take precautions in all areas that can harbour ticks.

**How to protect yourself in Lyme habitat:**

- wear light colored clothing, long sleeves and pants
- tuck pants into socks
- cover, braid or tie long loose hair
- spray clothing with repellent (including shoes)

Once home......

- throw clothing into the dryer on high heat
- have a shower and check dark, moist areas: hair, cracks behind ears, knees, elbows, underarms, crotch etc. for ticks
If you are bitten

The following link gives a summary of which ticks are capable of transmitting lyme:

http://canlyme.com/lyme-basics/tick-id/

Since the difference between an easily treatable case of Lyme and one that can take months to years to treat can be as little as several days, if you have been bitten by a Lyme carrying tick then you should consider immediate preventative antibiotic treatment (with at least a twenty day treatment course). If you are not certain of the type of tick, it can be sent in for identification (but still consider starting antibiotics until the infection potential is ruled out). If you develop symptoms after a tick bite and continue to exhibit symptoms after an appropriate course of antibiotics, they should be continued. For specific information on drugs, doses and length of treatment see the page, "Acute and Preventative Treatment."

A bulls eye rash is diagnostic of Lyme and should be treated immediately with a full course of antibiotics without the need for supporting Lyme disease bloodwork or tick testing. Lyme rarely shows up in bloodwork when it is first contracted, and the time waiting for test results may result in the illness progressing to a later stage. Be aware that early antibiotic treatment also will result in a negative test regardless of whether you have lyme.

removing a tick:

Remove the tick promptly as the risk of infection increases the longer the tick is attached.

To prevent the release of gut contents (which increases the risk of infection):

do not:

- burn with match
- suffocate
- squeeze body

do:

- use narrow nosed tweezers
- grab near mouthparts as close to the skin as possible
- pull the tick firmly and straight out
lyme signs...

"It is frequently believed that the most common sign of Lyme disease is inflamed, swollen joints. Although this classic joint involvement does occur in a small percentage of people, the larger majority who have joint involvement experience joint pain that comes and goes, wanders from one area of the body to another and includes pain in the muscles, tendons and ligaments around the joint. It very often does not include any redness or swelling."
- Dr. Marty Ross, LLMD

"Less than 50 percent of people diagnosed with Lyme disease recall having been bitten. Bites are painless and ticks in their nymphal and juvenile stages are smaller than a poppy seed or pin head and exposure is very easy to miss. Symptoms may appear immediately, weeks or months or even years after. Lyme disease can hide from the body and immune system in a cyst form."
- Dr. Marty Ross

The classic bullseye rash occurs less than 40% of the time.

Lyme disease can mimic many other illnesses and the list of possible signs include flu like illness and neurological signs such as blurred vision, vertigo, pronounced weakness and neuromuscular pain, headaches, numbness and even paralysis.
coinfections

Ticks can carry coinfections, so if you experience illness after a tick bite Lyme is not the only thing to consider. The three most common confections are:

Bartonella

Most common signs: sore soles, neurological symptoms out of proportion to normal lyme cases, severe anxiety, dry sweats, mood swings, cognitive difficulties, rash that looks like stretch marks and more.

Babesia

Most common signs: night sweats, panic attacks, frontal headaches, air hunger, racing or skipping heart and feeling off balance while walking.

Ehrlichiosis

Most common signs: sudden high fever, fatigue, muscle aches, headache. The severity can be mild to life threatening.

Other tick borne illnesses

Depending on geographic location, ticks can also spread infection of any of the following illnesses: Colorado Tick Fever; Mycoplasmas; Powassan virus; Q Fever; Rocky Mountain Spotted Fever (Rickettsia); Tick-borne Relapsing Fever; Tularemia.

Doxycycline, the drug of choice for preventing and treating early Lyme is also used to treat Ehrlichia, Anaplasma, Q Fever and Rocky Mountain Spotted Fever, but not Babesia or Bartonella. For more detailed information about assessing and treating coinfections see:

http://canlyme.com/just-diagnosed/co-infections/specific-co-infections/
Preventative and acute treatment

Because of a longstanding medical controversy over Lyme treatment and assessment guidelines in Canada, there are different opinions among doctors about what course of antibiotics should be taken for Lyme prevention and acute early Lyme symptoms. The preferred regimen for a tick bite without symptoms according to the International Lyme and Associated Diseases Society (ILADS) is 100–200 mg of doxycycline, twice daily for 20 days. They present research that suggests that less than this is not effective in all cases. If a bull’s-eye rash is present ILADS recommends 4–6 weeks of amoxicillin 1500–2000 mg daily in divided doses, cefuroxime 500 mg twice daily or doxycycline 100 mg twice daily or a minimum of 21 days of azithromycin 250–500 mg daily. And if Lyme symptoms are present at the end of the course it is recommended to continue antibiotic therapy until the symptoms are resolved. The Infectious Disease Society of America (IDSA) recommends shorter courses of treatment in all cases.

In my opinion, based on my own review of research as well as seeing many cases of Lyme be resolved under ILADS guidelines and people remaining sick when antibiotics are either not given or stopped too soon, finding a doctor willing to treat you under ILADS guidelines gives the best chance for prevention and recovery. A detailed manual of treatment guidelines by ILADS with supporting research can be found at:


Early Intervention is Key

If identified and treated immediately, a short course of antibiotics can completely cure the illness. As time passes, symptoms worsen and both treatment and diagnosis become more difficult.

Stage 1: Early infection (first few days after infection)

Stage 2: Infection spreads (days to weeks following infection)

Stage 3: Chronic Lyme (days to weeks after infection if left untreated or not properly treated for months/years after infection)

easily treated
can take up to a year to treat
treatment takes six months up to several years
Chronic Lyme treatment in Canada

The definition and treatment of late stage Lyme is the subject of the most significant and impactful controversy between the Infectious Disease Society of America (IDSA) standards of care and the standards developed by the International Lyme and Associated Diseases Society (ILADS):

The IDSA refutes the existence of chronic Lyme disease and the ability to treat a patient in the long-term.

ILADS presents research that contradicts the claims of the IDSA and doctors following ILADS protocols are treating chronic cases with high success rates. ILADS is calling for a change in treatment protocols.

Canadian standards currently presented to infectious doctors are based on the IDSA protocols, discouraging doctors from treating long term Lyme and creating huge resource gaps for late stage Lyme patients. Many Canadians seek help in the States because they cannot find a specialist in Canada.

I have seen many success stories come from long term Lyme treatment and there is mounting research evidence that Chronic Lyme Disease exists and is treatable:

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2876246/
For an account of the flaws in the IDSA review process see:
http://www.ilads.org/lyme/ILADSComent051915.pdf

Some really good news

Elizabeth May recently passed a private members bill that makes the creation of a national Lyme disease strategy law:
http://elizabethmaymp.ca/lyme-disease-legislation-there-ought-to-be-a-law-and-there-is/

This is an imminent opportunity for patient groups, doctors and administrators to collaborate and create more effective and inclusive standards of care for all Canadians affected by Lyme.

“the federal Minister of Health is now required to convene a federal/provincial/territorial conference, including medical experts and representatives of the Lyme Disease community, before the end of 2015. The goals include developing better strategies for prevention, speedy diagnosis, best standard of care for treatment, and further data collection and research.”

- Elizabeth May
Resources

Word of mouth among those being treated for Lyme is often the best way to find a Lyme literate physician near you. Dr.'s that I personally trust because of both their reputations and my experience with them are:

Dr Marty Ross, MD, Healing Arts Partnership, Seattle, USA

Webpage:  http://www.thehealingartspartnership.net

Dr Eric Chan, ND, Pangaea Clinic of Naturopathic Medicine, Richmond, BC

Webpage:  http://www.pannaturopathic.com

Marty Ross has also made up a treatment manual that can be followed by those who have Dr.'s willing to treat Lyme but without the know-how. There is a small monthly cost for access and the resource is far more valuable than the very minimal price tag.

http://www.treatlyme.net

He also hosts weekly free webinars:

http://www.treatlyme.net/marty-ross-md-conversations/

There are a number of Canadian and international initiatives supporting Lyme disease research, education, support and the establishment best practices:

The Canadian Lyme Disease Foundation (CanLyme) was formed to provide the public, including medical professionals, with balanced and validated information on tick borne illnesses, as well as volunteers that can provide information and support.

http://canlyme.com

ILADS (International Lyme and Associated Diseases Society) promotes understanding of Lyme and its associated diseases and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

http://www.ilads.org

The Lyme Disease Association of Alberta (LDAA) is a non-profit organization created to provide Lyme disease awareness & prevention information to Albertans. As well, the organization strives to provide support to patients, caregivers, and families affected by Lyme disease.

http://albertalyme.org

http://albertalyme.org
Igenex

Igenex in California is a reputable private lab offering blood test for Lyme disease and co-infections:

http://www.igenex.com/
Website/#

Note: The Western blot is the current gold standard for testing for Lyme disease, but like all test it has limitations and should be only one part of the assessment process. Others considerations include history of symptoms, tick bites and visits to Lyme endemic areas. Since Lyme can mimic so many other illnesses, ruling these illnesses out should also be part of the assessment process.

Sources


about Sarah

Sarah Hutchison grew up in Calgary, Alberta and moved to the Rocky Mountains of Canmore in 1995 where she quickly began building a community through her passionate embrace of mountain life. Backcountry skiing, biking, climbing, enjoying music, dancing, and traveling are just a few of Sarah's many passions.

After an infected tick bit Sarah, her story changed. In 2008 she developed Lyme disease and the co-infection bartonella. Struggling with nerve pain and weakness in her limbs hands and spine, fatigue, vertigo and vision problems, Sarah had to completely alter her activities and step away from her career as a psychologist.

In an effort to continue to contribute to the prevention of suffering and healing of others she does what she can to promote Lyme awareness. To learn more about Sarah and about the experience of Lyme see her blog at: foxnsox.wordpress.com

Sarah wants to make this e-booklet widely available at no cost. If you would like to contribute something to Sarah to help her with her treatment costs, see the following online fundraising link: http://www.gofundme.com/shakeofflyme