

Lyme disease: Some BIG questions!

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Borrelia *burgdorferi* bacteria and borreliosis

- The information I am presenting today on Lyme disease, or borreliosis, or borrelia burgdorferi bacteria is:
 - 1) based on one NW resident's experience – mine
 - 2) evolving daily as I learn with Lyme organizations, researchers, websites, books, drs, patients, etc.
 - 3) a series of questions and controversies representative of my learning about Lyme and related issues since August of 2013

Who's here?

- Watched a documentary? Read article(s)?
- Have a friend or family member with symptoms?
- Medical interest?
- Different professional interest?
- Wondering about our area?
- Have curious symptoms yourself?

Test - true or false?

1. Lyme disease is rare in Canada
2. Doctors treating Lyme disease effectively may face investigation and lose their medical license in Canada
3. Lyme disease is only transmitted by Black legged deer ticks
4. *Ixodes pacifica* ticks are the main Lyme carrier in BC
5. Lyme disease, or Lyme borreliosis, is an acute bacterial infection
6. 2-4 weeks of antibiotics generally cures Lyme disease
7. Canadian treatment protocols are based on current and effective international treatment guidelines

Some major Lyme questions...

- **WHAT:** Lyme borreliosis and co-infections
- **WHERE:** Everywhere: particularly in endemic Lyme areas
- **WHEN:** Ancient times, 20th century, and current information. Fall and spring peaks.
- **WHY:** Experimentation with bio- zoonotic weapons, WWII - Black Forest lab, 1950's+ Plum Island lab release, 1977 Lyme, Connecticut
- **WHO:** North America's fastest growing vector born infectious disease; globally an issue, particularly in Germany, Russia, Japan, US.

Ticks are a common transmission vector of Lyme disease

eg. (W.) black legged ticks, Lone star ticks, ...

March 24, 2014



Vectors of transmission

Ticks are most researched –
Adult stage
Nymph stage
Larval stage

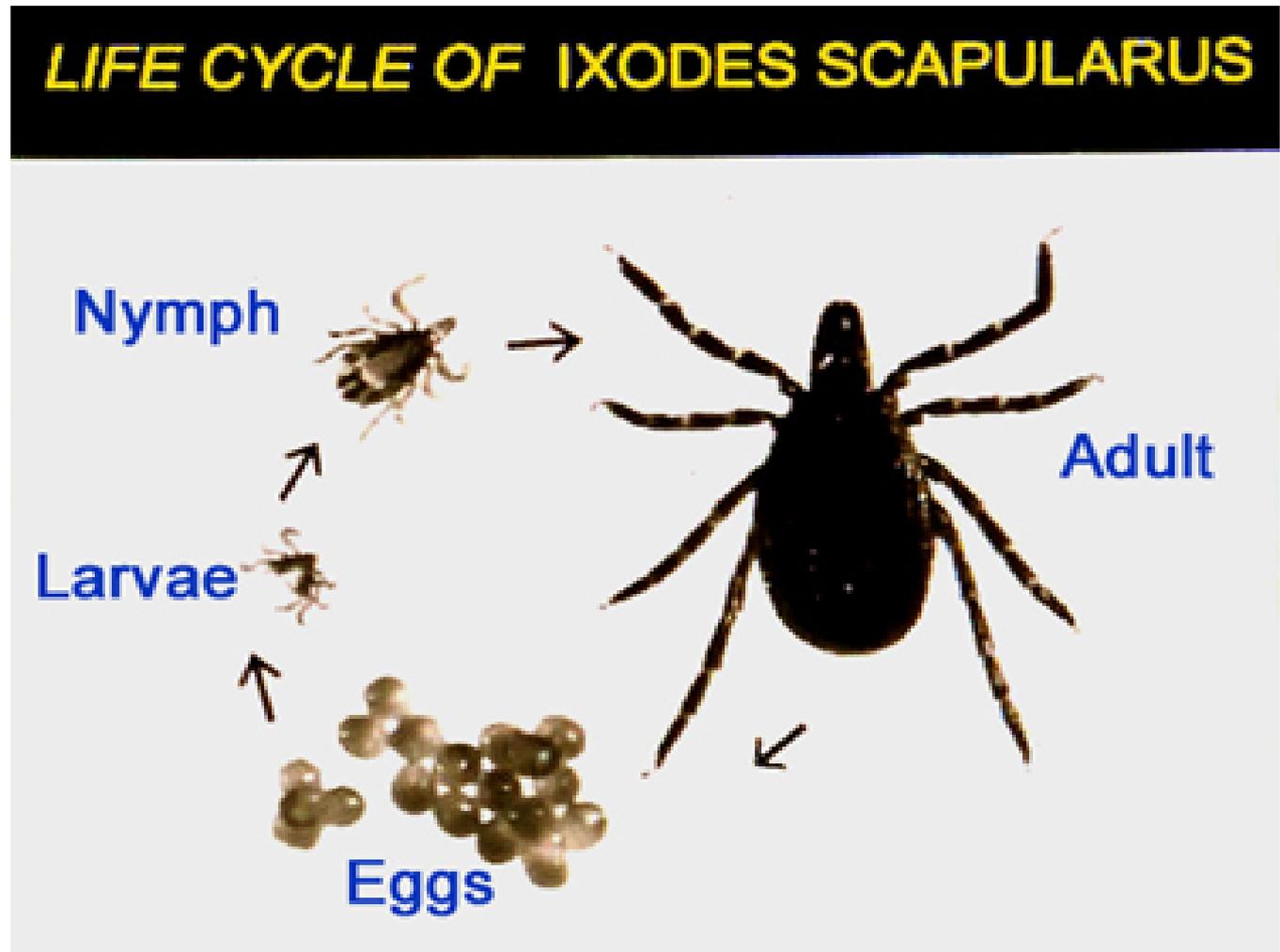


A young tick, small as a period. can transmit infection: as can other insects; mosquito, flea, mite, horsefly, spider...



Life cycle of 1 host

- Each of 3 stages needs Mammal host
- Bb infected ticks can transmit Lyme in each stage – adult to eggs.



Most common tick carriers:

- “In Canada, the blacklegged tick (*Ixodes scapularis*, which is becoming established from Manitoba eastwards) and the western blacklegged tick (*Ixodes pacificus*, which occurs in British Columbia) are the species that transmit *B. burgdorferi*. These ticks can also carry other less common infectious agents. Other tick species are known to transmit the bacterium that causes Lyme disease in nature, but these ticks live in the nests and burrows of their wild animal hosts and rarely bite humans”.
- <http://www.phac-aspc.gc.ca/id-mi/tickinfo-eng.php#sec-2.3>

Some preferred hosts in IS tick life cycle...



People!

Lyme aspects debated

- **Vectors of transmission**, and endemic areas changing
- **Bacterial strains**: eg. 130+Bb bacteria, variety of infection forms (spirochete/cell wall, blebs, biofilms, cystic, intracellular vacuoles – dormant forms, Bb morphs over time)
- **Multiple coinfections** complicate all stages of Lyme: babesiosis, bartonella (many forms), ehrlichia, mycoplasma, RMSFever...
- **Testing**: limitations and possibilities given timing, variety
- **Symptoms**: bite site, EM rash only sometimes, flu-like variety and migration of symptoms (eg. joint, muscle, nerve)
- **Treatment**: None, allopathic, naturopathic, and combined
- **Prognosis**: acute: short range and chronic: long range
- The need for local, national, international **bacterial responses** and what kind of response (chickens?)

Controversies around Lyme...

- Often depend on the perceiver's:
 - Perspective
 - Lens of interest (patient, doctor, lab, media...)
 - Background knowledge
 - Purpose, use of Lyme information
 - Experience with Lyme
 - Urgency with results (treatment, political, lab \$)
 - Skill level in assessing information and sources
 - Desired outcome (treatment, business, research)

Perspectives on Lyme

- Our career, perception, knowledge base, information gaps, experience with Lyme, sensory acuity, etc. all influence how we process information.



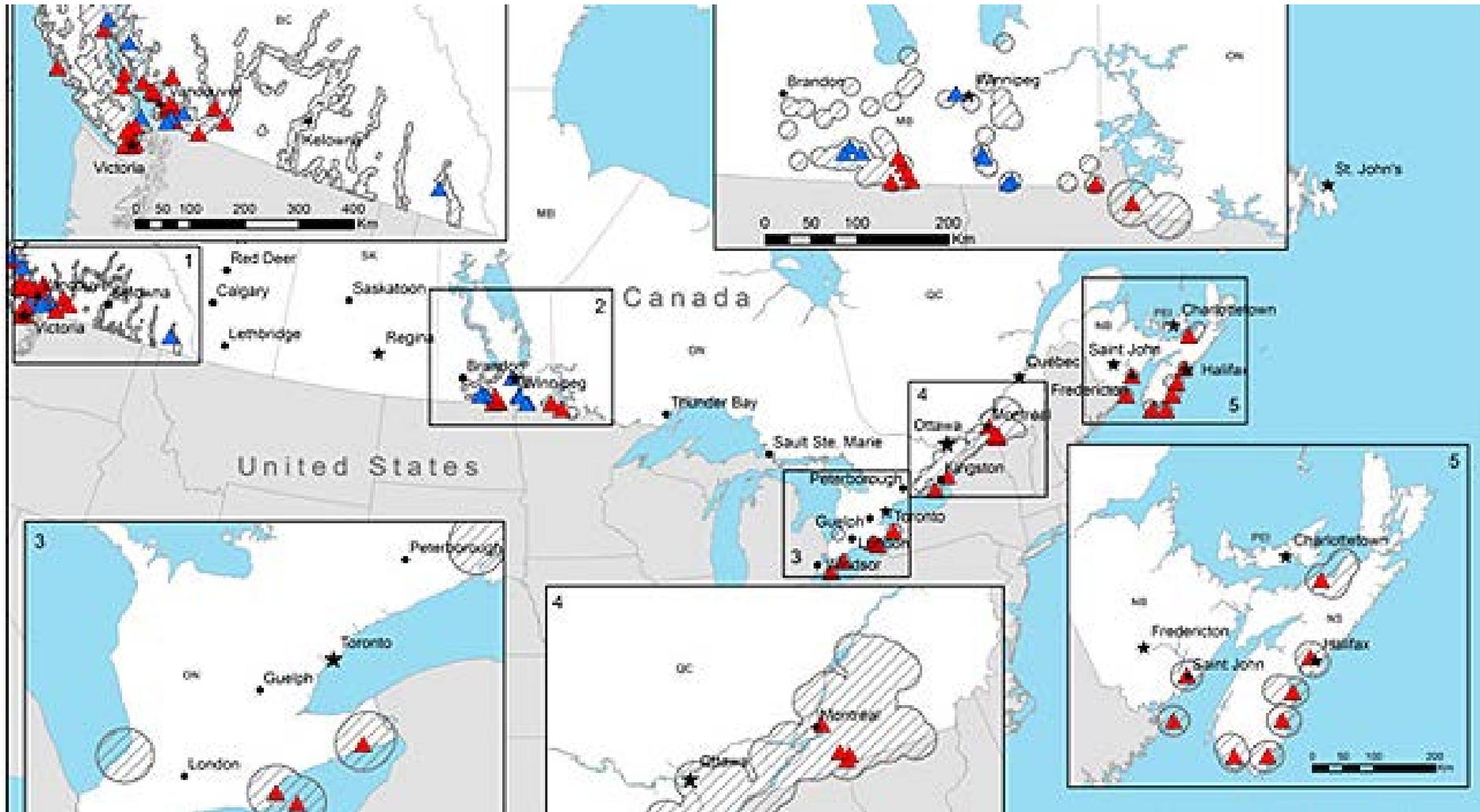
- *Let's look at how lively and different our information systems are...*
- ... make a picture in your mind of a photographer setting up a great shot. What do you imagine?

What did you see ... ?



Endemic areas in Canada

<http://www.phac-aspc.gc.ca/id-mi/tickinfo-eng.php#sec-2.3>



BC Lyme distribution, 2013

[http://www.bccdc.ca/resource-gallery/Documents/Statistics and Research/Statistics and Reports/Epid/Vektor-bourne/Lyme Disease Risk Areas Map BC June 2013.pdf](http://www.bccdc.ca/resource-gallery/Documents/Statistics%20and%20Research/Statistics%20and%20Reports/Epid/Vektor-bourne/Lyme%20Disease%20Risk%20Areas%20Map%20BC%20June%202013.pdf)

Some perspectives include...

- Patients – recovered, recovering or untreated, and their families
- Doctors and researchers – 1) internationally collaborating for effective treatment, 2) new to Lyme in their community, 3) influenced by health insurance, or pharmaceutical industries, 4) patients themselves, 5) funded by insurance or pharmaceutical companies, 6) starting their own labs or research facilities, 7) being investigated.
- Economic, military, media, homeland security, regulatory and political interests

Patients often...

- Do not remember a tick bite
- Do not remember early symptoms (often flu-like)
- Do not go to a doctor for some time, until symptoms worsen, and/or disseminate throughout the body and intensify
- Think there is an accurate test for Lyme disease
- Think Canada is using international and effective treatment protocols, diagnostic tests, and co-infection follow up (these are available)



“Bulls eye” rash question

- 2 – 50 % of patients remember such a rash or have it in doctor’s office.
- Required for Lyme disease diagnosis, or testing, by some insurance or medical guidelines

Other rashes may look like...



Origins controversy

- Dr. Traub, WW II, Traubingen lab, Black Forest of Germany, WWII (currently high incidence area for ticks and infections)
- Dr. Traub, 1950's, Plum Island, US military lab off the coast of Long Island New York (Connecticut and New York early high incidence areas)
- Bio-agent lab de-militarized, extensive security de-funded –civilian facility with US Department of agriculture, FDA, then to Homeland security
- Multiple investigations initiated, including Governor Cuomo and Governor Clinton following Lyme, Connecticut outbreak of “juvenile arthritis” and connections with multiple bacterial and co-infections spreading rapidly on the east coast.
- See citation: Lab 257, authored by lawyer Michael Carroll

Testing controversy

- There are no reliable single tests for Lyme disease, acute, disseminated, chronic, or in remission (dormant).
- Ticks sent in for testing need to be live (BC)
- There are multiple indicators. A single ELISA blood test may or may not be timed with spirochete presence.
- Western blot follow up for borrelia DNA and host genetic markers depend on varieties (bands on Western blot) tested for, which is location specific (eg.. Scotland)
- Clinical diagnosis is needed to assess Lyme and co-infection indicators, map out symptoms in body systems, and follow up treatment successes and gaps with further testing and new protocols pulsed over time with bacterial cycles (days, weeks, seasons)

Testing

- According to the Centre for Disease Control, Lyme disease should be determined using a clinical diagnosis, meaning that the physician makes the diagnosis using your clinical history and symptoms. Lab tests should only be used to confirm a clinical diagnosis.
- However, many physicians in Canada still depend on a test-derived diagnosis before treatment will be given. The problem is that the two-tiered testing protocol used in Canada and the US is riddled with false negatives and is unable to detect all bacterial strains and co-infections.
- As well, the first test—the ELISA—is ineffective in detecting the infection in its early stages. A negative test means the second phase—the Western Blot—isn't applied, and closes the door on further testing and treatment.
- <http://www.infocusmagazine.ca/2015/ticking-time-bomb/>

Symptom controversies

- **“Classic” Lyme** – bite, rash, site reaction, flu-like, followed by migrating, cyclic symptoms:
- **Neurological**: CNS or peripheral nervous system
- **Dermatological** – rashes, lesions, discoloration
- **Ophthalmological** – blurry, sharp pain, double
- **Joints** (+tendons, ligaments): “popcorn neck”, particularly knees; hands and feet
- **Musculature** – fibromyalgia, ChronicFS, lupus
- **Lymph/venous** insufficiency

Symptoms controversy (cont'd)

- Recent, acute inflammation, disseminated, & chronic forms present different symptoms.
- Body system impacted may be single or multiple (eg. “Lyme arthritis” in one knee, or general fibromyalgia throughout muscles)
- Symptoms are migratory and cyclic (eg. change joints) and intensify in approx 4 wk cycles)

Progressive symptoms

- “Once the Lyme-causing bacteria is inside of a person, **the spirochete can drill through tissue** and can embed itself in the central nervous system, heart, brain, liver, spleen and joints. These highly evolved microbes cause a host of symptoms ranging from dizziness to paralysis.
- **Infected individuals report varied symptoms:**
flu-like symptoms, fatigue, neck stiffness, jaw discomfort and swollen glands. Nervous system abnormalities include memory loss and partial facial paralysis (Bell’s palsy). Peripheral neuropathy, migratory joint pains and pains in the tendons, muscles and bones may occur later in the disease.
- **More subtle changes** such as memory loss, difficulty with concentration, and a change in mood or sleeping habits have also been associated with Lyme disease. The sheer **range of symptoms** of Lyme disease—there are more than 100—have caused this shape-shifting disease to be dubbed **‘The Great Impostor.’**
- <http://www.infocusmagazine.ca/2015/ticking-time-bomb/>

Common Co-infections ticks carry:

- Babesiosis
- Bartonella
- Ehrlichiosis
- Mycoplasma
- Human Granulocytic Anaplasmosis

Go to CANLyme for more on this...

- <http://canlyme.com/just-diagnosed/co-infections/specific-co-infections/>

Australian “imitation” diagnoses

- In Australia a **Lyme Disease** sufferer could be diagnosed with: Attention deficit disorder, Bell's palsy, Bipolar, Brain tumour, Chronic fatigue syndrome, Chronic pain disorder, Colitis, Crohn's disease, Depression, Diabetes, Alzheimer's disease, Eczema, Encephalitis, Fatigue, Fever, Fibromyalgia, Fifth's disease, Flea bite, Flu-like symptoms, Gastroesophageal Reflux disease, Headache, Hives, Hyperthyroidism, Hypothyroidism, Infectious arthritis, Insect bite, Interstitial cysts, Irritable bowel syndrome, Juvenile arthritis, Lupus, Ménière's syndrome, Meningitis, Migraine headache, Multiple sclerosis, Osteoarthritis, Parkinson's disease, Peripheral neuropathy, Poison ivy, Prostatitis, Psoriatic arthritis, Psychiatric disorders, Raynaud's syndrome, Reactive arthritis, Relapsing fever, Rheumatoid arthritis, Scleroderma, Sjögren's syndrome, Sleep disorders, Sunburn, Stiff neck, Thyroid disease, Thyroid disorders, Vitamin B12 deficiency.
 - These are just a few of the diagnosis that **Borreliosis** or The **Australian Lyme Like Illness** can present as.

Diagnostic controversy

- Which **Bb tests** are: 1) most reliable: stages
2) currently available
3) affordable for patient
- Which **symptoms** are: 1) most common
2) most frequent
3) specific/documented
- What are **exposure** factors 1) endemic area
2) bush/wildlife

Treatment

Book examples:

- Antibiotic considerations list – Burrascano
- Acute, systemic as well as site specific - Burrascano
- Resulting damage treatments, eg. collagen - Buhner (Verna – finding local resource option)

- Chart – see sample previous, babesia, CanLyme website

- Chronic? Yes, often because of the co-infections. Long term borrelia viability proven in dogs, mice and monkeys. Humans have transmitted borrelia spirochetes back to ticks in research a year after bite/treatment.

Treatment controversies

- Acute, disseminated, or after 1 year (chronic)
 - Allopathic and naturopathic:**
 - Antibiotics by mouth
 - Antibiotics via intravenous line or pic line
 - Combined antibiotics
 - Anti-microbial herbs
 - Combined antibiotics and anti-microbial
 - *Also supplements, diet changes, exercise, therapies, pain or insomnia interventions, and so on

Research areas impacting treatment...

- cold **body temp**, changing pH & blood sugar, **bacteriophages**-meta immune cells adaptogenic for 85/15 balance of microbiome (Jerrigan);
- **heat signatures** of chronic bacteria (CSUSF);
- **new strains** of both borrelia (miramotti) and bartonella found in US, biopsies versus blood cultures (Horowitz);
- **persister/dormant** cells inside host protein encased spirochete cystic forms, matrix spirochete biofilms, vacuoles of gram negative bacteria, eg. inside RB cells-different from antibiotic resistant bacteria (Buhner, Schmidt).
- 45° toenails, example of a unique strain symptom from UK.
- **Pulsing, rotations, alternating** antibiotics, herbs, support therapies, available in Europe (ILADS).

Framework on Lyme Disease Act

...First introduced in June 2012, **Bill C-442** was passed unanimously with multi-partisan support in the House of Commons in June 2014. It will establish a framework for collaboration between the federal, provincial and territorial Health Ministers, representatives of the medical community, and patients' groups to promote greater awareness and prevention of Lyme disease, to address the challenges of timely diagnosis and treatment, and to push for further research. ...

"C-442 is now the **first piece of Green Party legislation in Canadian history,**" stated Bruce Hyer... Although it is rare for private member's bills to be passed through both the House and Senate, Bill C-442 has received multi-partisan support from Senators and Members of Parliament, in addition to the Canadian Medical Association, the College of Family Physicians of Canada, and the Canadian Lyme Disease Foundation.

"Now that the bill has passed, I look forward to working with all relevant interest groups and governments, under the guidance of Minister Ambrose, for the **national conference to develop the federal framework**, as detailed in the bill, to deal with this dreadful illness," concluded Elizabeth May.

Medical controversy – *treatment* continuum

- Some doctors treat both **classic or individually documented exposure and symptoms – to full health** – with or without out positive lab results
- Some doctors treat **only classic symptoms with positive lab tests (blood tests) in narrow range** of Bb antibody production and confirmed Bb DNA, and for only a short period of time, orally
- Medical researchers look at both or either and publish with or without identifying which key factors were involved, or conflicts of interest.

Prognosis controversies

- Acute symptoms in first weeks easily treated with short term antibiotics. Relapse may require longer course of medication.
- Disseminated symptoms in first months may require longer courses of treatment and combinations of antibiotics, plus naturopathics, plus nutrition, etc
- Does Late stage or chronic Lyme borreliosis exist?
How long is IV and other treatment required? Why do some patients not respond to even extended treatment?

Political controversy

- How did this epidemic of Lyme disease begin?
- Should Lyme patient care be funded?
 - publicly? Privately?
 - from acute to chronic, and to full health?
- What are the most effective Lyme reduction or prevention strategies?
- Who should be taking action? National? Int'l?

What to do if you or a loved one have Lyme-like symptoms

- Document the history of the symptoms
- Document your risk factors
- Keep a symptom and intervention log – look for symptom migration, cycles and successes
- Contact closest Lyme literate organization and learn about testing and treatment options in your area
- Work with your health team to decide on US, German, or other available testing and treatment for both borreliosis, coinfections and specific symptoms
- Continue treatment by symptom response – 3-12 months with no symptoms

Prevention

Protective clothing includes a hat, long-sleeved shirt, and long trousers tucked into socks or boots. Light-colored clothing makes the tick more easily visible before it attaches itself. People should use special care in handling and allowing outdoor pets inside homes because they can bring ticks into the house.

Permethrin sprayed on clothing kills ticks on contact, and is sold for this purpose. **Insect repellents with Picaridin, IR3535, DEET, or oil of lemon eucalyptus repel ticks**, as well.[118]

A community can reduce the incidence of Lyme disease **by reducing the numbers of primary hosts** on which the deer tick depends, such as rodents, other small mammals, and deer. Reduction of the deer population may, over time, help break the reproductive cycle of the deer ticks and their ability to flourish in suburban and rural areas.[119]

An unusual, organic approach to control of ticks and prevention of Lyme disease involves the use of **domesticated guineafowl**. Guinea fowl are voracious consumers of insects and arachnids, and have a particular fondness for ticks. Localized use of domesticated guinea fowl may reduce dependence on chemical pest-control methods.[120]

<http://forum.stopthehogs.com/phpBB2/viewtopic.php?t=2229&p=3935>

Retrieved on 2 16 2016 from:

[WATCH: Elizabeth May to Testify on Bill C-442 - Lyme Disease](#)

Post-test - true or false?

1. Lyme disease is the fastest growing vector borne infectious disease throughout North America
2. Lyme disease/co-infections are easily treated with antibiotics and natural antimicrobials
3. Doctors treating chronic Lyme disease effectively may be investigated/lose their medical license in NA
4. Black legged deer ticks are the only BC Lyme transmitters
5. Lyme borreliosis, is a) an acute/localized, or b) acute/disseminated, or c) chronic/disseminated or d) and of these, bacterial infection

Post-test (cont'd)

6. 4 weeks of antibiotics may cure recent, acute, localized Lyme with coinfections.
7. Multiple treatments are needed over time for disseminated or acute Lyme disease, with or without coinfections.
8. Lyme infection symptoms are cyclic , have dormant cycles, and are recurring in a variety of forms: spirochete, biofilm, cystic, blebs, vacuole and/or round forms?

Post-test (cont'd)

6. Canadian treatment protocols are based on early 2000, US ISDA guidelines.
7. The US guidelines were influenced by health insurance, vaccine, patent (1980's – live materials) and pharmaceutical interests.
8. The authors were discredited for conflicts of interest in lengthy investigation by the Attorney General of Connecticut, begun in 2006. Richard Blumenthal enforced agreements and required repeated votes, but representatives were again hand-picked over time to favour status quo. A settlement occurred.
12. Re-activation of dormant diseases complicates treatment (chicken pox, shingles, Herpes, post polio syndrome, and so on).

References

- Buhner, S. H. (2013). *Healing Lyme disease coinfections: C*
- Ferrie, H. (2010). *Ending denial: The Lyme disease epidemic, a Canadian public health disaster*. Caledon, Ontario: KOS Publishing Inc.
- Horowitz, R. (2013). *Why can't I get better? Solving the mystery of Lyme and chronic disease*. New York, New York: St. Martin's Press.
- Schmidt, B. (2010). *Chronic Lyme disease in British Columbia: A review of strategic and policy issues*. May 31, 2010. Provincial Health Services Authority.
- Weintraub, P. (2013). *CURE Unknown: Inside the Lyme epidemic*. New York, New York: St. Martin's Press. (Winner of the American Medical Writer's Association Book Award).

References

- <http://canlyme.com/>
- www.ilads.org
- [BCLyme](http://www.bclyme.com)
- www.murakamicentreforlyme.org/

- <http://www.infocusmagazine.ca/2015/ticking-time-bomb/>

- http://www.magnotta.com/Magnotta_Fights_Lyme.aspx

- <http://www.phac-aspc.gc.ca/id-mi/tickinfo-eng.php#sec-2.3>

Resources

Lyme Disease -- History and Current Controversies, Dec 9, 2013

- [University of California Television \(UCTV\)](#)
- <https://www.youtube.com/watch?v=yC IEERJXSA>

A lawyer's research prior to Governor's Cuomo and Clinton investigations:

- Carroll, Michael Christopher. *Lab 257: The Disturbing Story of the Government's Secret Germ Laboratory*. New York: HarperCollins Publishers. [ISBN 0-06-001141-6](#). August 9, 2005

Under Our Skin – video 1 (2008) and 2 (2013) 25.00 from website

- Under Our Skin - Dr. McDonald Clip, Lyme Disease, Alzheimer's, MS, ALS
- <https://www.youtube.com/watch?v=GCLwauRh2gQ>

Resources (cont'd)

[Dr. Joe Burrascano's Treatment Guidelines - Lyme Disease ...](#)

- www.lymenet.org/BurrGuide200810.pdf
- JOSEPH J. BURRASCANO JR., M.D.. Board Member,. International Lyme and Associated. Diseases Society. DISCLAIMER: Information...

Dr. Richard Horowitz at the Cambridge Hyatt in MASS, speaking at a Symposium on Tick-borne diseases

- <https://www.youtube.com/watch?v=O9a-2Nb2sbk>
- **Dr. Burrascano & Dr. Nicola McFadzean** in new "Beginner's Guide to Lyme Disease"
- **A Calgary case study**, written by Theresa & John Stadnick
www.pushing-past-excuses.com/2/post/2015/06/lyme-disease-our-fight-to-pay-it-forward.html

<https://www.lymedisease.org/lyme-basics/lyme-disease/chronic-lyme/>

- Research up-date on chronic Lyme (over 6 months, still symptomatic).
- Lymedisease.org
- (Board of directors includes professors, lawyers, pharmacist, research scientists, patients, doctors, authors, diagnosticians, and so on)

Resources (cont'd)

- Suzuki, D. (Narrator). (July 14,2014). *Ticked off: The mystery of Lyme disease*. CBC Television, Nature of Things
- <http://www.cbc.ca/player/Shows/Shows/The+Nature+of+Things/ID/2411526805/>

Websites

- <http://www.ilads.org>
- <http://www.idsociety.org/>
- <http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/lyme-eng.php>
- <http://www.cdc.gov/lyme/>

Lyme Disease in Canada (top 2) & BC (bottom 2):

- <http://www.canlyme.com>
- http://www.phac-aspc.gc.ca/about_a_propos/engagement-participation/lyme-consultation-eng.php
- www.murakamicentreforlyme.org/
- <http://www.bcwomens.ca/our-services/specialized-services/complex-chronic-disease-program>

Thanks for coming out today!