2012 Canadian Lyme Disease and Coinfection Survey

Contact Information:

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This survey has been prepared by Marianne Middelveen, a Microbiologist who has personally experienced difficulties obtaining diagnosis and treatment for Lyme Disease. This prompted her interest in researching the extent of this problem throughout Canada with the hope of compiling information which might be useful in influencing changes in the current attitude towards the disease. Participation in this survey is voluntary, but your cooperation is strongly encouraged to give statistical weight to the study.

A parent or legal guardian must provide consent for minor children and/or may provide the information on their behalf. The identity of participants is strictly confidential and will not appear in any published statistics associated with this survey. Information (except for the identity of the participant) provided by the survey will be used for statistical analysis and may be part of a publication or a report associated with this survey. Information provided herein will not be used without permission of the participant or, in the case of a minor child, permission of a parent or legal guardian on their behalf. Results will be used to better understand the incidence and importance of Lyme Disease in Canada.

Marianne can be contacted by any of the means above for additional information, clarification of questions, and for her credentials as a researcher. She will also be happy to do the survey by telephone if you prefer.
Circle, underline or answer where appropriate. If needed you may write additional details or explanations on a separate sheet.

1) Resident of Canada? Yes     No

2) Gender? Male     Female

3) In which age bracket do you fall?
   0 to 18
   19 to 30
   31 to 45
   46 to 60
   60 and over

4) Do you believe you have Lyme Disease? Or have had it in the past? Yes     No

5) Have you had a known tick bite (tick was attached)? or tick bites? If multiple bites occurred at different times you may provide details concerning when and where you were bitten on a separate page.
   Yes     No

   If yes, where were you when you were bitten? (eg. Turkey Point Ontario, Vancouver Island or elsewhere) _______________________________________________________

   If yes, when were you bitten (month and year) _____________________________

   Was the tick species identified? Specify____________________________________

   Was *Borrelia burgdorferi* (Bb) detection from the tick attempted? Yes     No     Unknown

   Was Bb cultured from the tick? Yes     No     Unknown

   Was Bb DNA detected from the tick by PCR technology? Yes     No     Unknown

6) Have you ever had an Erythema migrans (bull’s eye rash)? Yes     No     Unknown

   A rash approx. 5cm or beyond that was not a bull’s eye shape? Yes     No     Unknown

   A red spot or lump that may have resulted from a tick bite? Yes     No     Unknown

   Multiple areas of rash or a rash covering large areas that might be secondary rash associated with Lyme Disease? Yes     No     Unknown
If yes, when (month and year) did the rash or rashes occur?
____________________________________________________________

If yes, where were you when the rash or rashes occurred (country, state/Province)?
______________________________________________________________________

5) Have you ever visited an area endemic for Lyme Disease?  Yes  No  Unknown
If yes, specify ___________________
If yes, when (month and year) did this visit occur? ________________________

6) Where do you think you may have contracted Lyme Disease? If more than one possibility you may provide details on a separate page ranking the order from most to least likely.
   In Canada, or USA – specify country and province/state, and other details you would like to disclose_________________________________________________________
   Outside Canada or USA – specify location and other details ___________________
   Unknown
   Do you have any evidence to support your suspicion?
   Yes  No  If yes, specify______________________________________________________

7) Do you, or did you have clinical symptoms consistent with Lyme Disease?  Yes  No
   When did the symptoms begin (month and year)?_______________________________
   Arthritis/Myalgia?  Yes  No
   Neurological manifestations?  Yes  No
   Cardiac symptoms?  Yes  No
   Peripheral neuropathy?  Yes  No
   Fatigue  Yes  No
   Cognitive dysfunction  Yes  No
   Other?  Yes  No  If yes, specify_____________________________________________

8) Have you been diagnosed with Lyme Disease?  Yes  No
   What date, month and year, was the diagnosis made __________________________
   By a medical doctor/physician/MD in Canada?  Yes  No

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If yes specify province ______________________________________

Did you pay a fee for the consultation not covered by Provincial Health? Yes  No

By a medical doctor/physician/MD outside Canada? Yes  No
If yes, specify location (country and state)____________________

By a naturopathic doctor/ND either inside or outside of Canada? Yes  No
If yes, specify location (country, province/ state)____________________

By a health care practitioner not included above? Yes  No
If yes, specify profession ___________________________________________
and location (country, province/ state)_________________________________

9) Have you had Lyme Serology (tests detecting antibodies reactions to Bb)? Yes  No
If you need help understanding testing, please call or e-mail.

If yes, which of the following apply to you?

Tests performed at a Canadian Laboratory? Yes  No
Were the results: Positive? Negative? Indeterminate/Intermediate?
If Indeterminate/Intermediate please explain ______________________________

specify province ____________________, laboratory name ______________________

A screening ELISA or IFA to Bb performed by a lab outside Canada? Yes  No
If yes, specify laboratory and its location ______________________________

CDC-Positive Western Blots performed by a laboratory outside of Canada? Yes  No
If yes, specify laboratory and its location ______________________________
If yes was this IgM or IgG or both? ______________________________

Positive Lyme serology performed by a laboratory outside of Canada? Yes  No
If yes, specify laboratory and its location ______________________________

Negative Lyme serology performed by a laboratory outside of Canada? Yes  No
If yes, specify laboratory and its location ______________________________
If yes, did you have IND or + reactions suggesting possible infection? Yes  No

Positive detection of antibodies to C-6 peptide or VlsE Yes  No

If yes to any of the above, can you provide banding patterns or are you willing to provide
a copy of the results? If yes, please provide with personal identifying information
removed.
10) Have you had other laboratory tests for Lyme Disease? (Examples: positive Bb culture, Lymphocyte transformation test, Antigen detection, PCR detection of Bb DNA?)

If yes, specify or circle test(s) above _____________________________

Other test not mentioned above _____________________________

Results: Positive   Negative   Other? _____________________________

Specimen type, ie. Blood, serum, urine, CSF, biopsy _____________________________

If yes, specify laboratory (ies) and location (country, province/state) of test(s) _____________________________

Are you willing to provide a copy of any test results?  Yes  No

If yes, please provide with personal identifying information removed.

11) Have you had additional tests that may indicate Lyme Disease? (Examples: CD-57 Stricker panel, SPECT scan, MRI, Cardiac tests)

If yes, specify or circle test(s) above _____________________________

Other test not mentioned above _____________________________

Please explain results: _____________________________________________

If yes, specify name and location (country, province/state) of test(s) _____________________________

12) Have you ever been diagnosed with any of the following illnesses?

Multiple Sclerosis?  Yes  No

Chronic Fatigue Syndrome  Yes  No

Fibromyalgia?  Yes  No

Rheumatoid Arthritis?  Yes  No

Amyotrophic Lateral Sclerosis (ALS)?  Yes  No

Systemic Lupus Erythematosus (SLE)?  Yes  No

Mental illness?  Yes  No

Parkinson’s Disease  Yes  No
Other disease or illness not mentioned above that has symptoms that could be
attributed to Lyme Disease?
If yes, specify ________________________________________________________________

Yes     No

13) Have you ever been diagnosed with a tick, insect borne, or other disease known to cause a
coinfection with Bb?

<table>
<thead>
<tr>
<th>Disease Description</th>
<th>Yes</th>
<th>No</th>
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<td>If yes, please specify disease and causative agent ________________________________</td>
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14) Have you been offered testing for any of the above coinfections? If so please indicate:

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15) Do you have laboratory evidence to support a coinfection diagnosis?

If yes, specify test __________________________________________________________________

If yes, specify lab and its location ______________________________________________________

Are you willing to provide a copy of any test results?  Yes  No
If yes, please provide with personal identifying information removed.
16) Have you ever been treated for Lyme Disease? 
   Yes     No

Are you currently undergoing treatment? 
   Yes     No

When did the treatment begin or end? _______________________________________

(If yes to either of the above, you may write any additional details regarding the treatment protocol and duration if desired.)

If you are being or have been treated, which of the following apply?

Antibiotic therapy in Canada? 
   Yes     No

If yes, specify province ________________________________________________

Did you pay a fee for the consultation not covered by Provincial Health? 
   Yes     No

   Were the antibiotics prescribed by a medical doctor/physician/MD? 
     Yes     No

   Were the Antibiotics prescribed by a naturopathic doctor/ND or other professional? 
     Yes     No

   If yes specify profession _____________________________________________

Antibiotic therapy outside Canada? 
   Yes     No

Antibiotics prescribed by a medical doctor/physician/MD? 
   Yes     No

If yes, specify location (country/state) ______________________________________

Antibiotics prescribed by a naturopathic doctor/ND or other professional? 
   Yes     No

If yes specify profession _________________________________________________

If yes, specify location (country/state) ______________________________________

Naturopathic therapy inside or outside of Canada? 
   Yes     No

If yes, specify location _________________________________________________

17) Have your symptoms:

   Improved after treatment? 
     Yes     No

   Worsened? 
     Yes     No

   Remained the same? 
     Yes     No

   Or are you still receiving antibiotic or other therapy? 
     Yes     No
If yes, are you experiencing a change in your symptoms?  
Yes  No

If yes, specify change ____________________________________________

18) Do you consider your treatment to be successful?  
Yes  No  Undecided

If yes to Question 13, have you ever been treated for a coinfection?  
Yes  No

Are you currently undergoing treatment?  
Yes  No

(If yes to either of the above you may write any additional details regarding the treatment protocol and duration if desired.)

If you are being or have been treated, which of the following apply?

Antibiotics or other prescription drugs specific for your coinfection (s)?  
Yes  No

If yes, specify country, province/state ________________________________

Are the drugs prescribed by a medical doctor/physician/MD?  
Yes  No

Naturopathic therapy in or outside Canada?  
Yes  No

If yes, specify location__________________________________________

Antibiotics or prescription drugs prescribed by a practitioner not included above?  
Yes  No

If yes, specify profession _________ and location ____________________

If yes to any of the above, when did the treatment begin and what is/was the duration of treatment?  ______________________________________________________

20) If yes to any part of Question 18, have your symptoms improved?  
Yes  No

Are you still receiving treatment?  
Yes  No

If yes, did you or are you experiencing a change in your symptoms specifically related to treatment of the coinfection (s)?  
Yes  No

If yes, specify change ____________________________________________

21) How would you rate your quality of life? Circle response(s) which apply

a) never been treated  Excellent,  Good,  Adequate,  Poor
b) post-treatment  Excellent,  Good,  Adequate,  Poor

c) pre-treatment  Excellent,  Good,  Adequate,  Poor

d) currently being treated  Excellent,  Good,  Adequate,  Poor