

February 15, 2015

To all Ontarians affected by Lyme disease,

In November of 2014, the Ontario government unanimously voted "yes" to a motion that called for the development of a provincial strategy for Lyme disease. The Ontario Lyme Alliance has been working hard to advocate for patients in Ontario and Mr. Michael Mantha, Algoma-Manitoulin MPP, supported us by offering to present this motion. The wording of the motion can be found on our website: <http://www.ontariolymealliance.ca/#motion>.

Now we need patient statements that will explain to the strategy committee the ways in which Lyme disease has affected Ontarians. **That's where you come in!**

Lyme patients can contribute to the development of this strategy by **writing a letter that describes your own experiences with Lyme**. Your submission can be sent to: contact@ontariolymealliance.ca. Family members or caregivers are welcome to write on behalf of a patient who is unable to write their own statement.

Are you unsure of what you should include in your letter? Don't worry! We've written up a list of suggestions of things that you might talk about in your letter. Please do not feel overwhelmed by the length of the list! **We suggest that you don't try to include everything below but instead choose what parts of your story you think will be the most impactful.**

Some of the things you might choose to write about include:

Personal History

- Where and when you were bitten, if you know. Be as specific as you can about the location.
- How long you have been sick.

Prior Awareness

- Your awareness of ticks and Lyme disease prior to being bitten and infected. Tell them if you felt aware and informed about the severity of this disease and the risk of being bitten by infected ticks in Ontario.

Diagnosis

- Your experiences when you first sought medical attention in Canada (for example, a lot of patients are told that their rashes are not due to Lyme [remember that even rashes that aren't "bull's eye" rashes can be from Lyme bacteria], or that their symptoms are just the flu).

- Whether or not you received a diagnosis of Lyme by a medical physician in Canada. Tell them if you think your family doctor would not be able to recognize Lyme if they saw the symptoms in other patients.
- How long it took you to receive a diagnosis.
- For those who were diagnosed with Lyme in Canada, what treatment was prescribed and for how long (but do not mention the names of any physicians who have treated you!).

Testing

- Your experience with blood testing for Lyme in Canada. If your doctor never tested you for Lyme, be sure to state that.
- If you received blood testing in Canada, mention any positive or negative results on the ELISA test or the Canadian Western Blot (for the latter, if you were positive, state whether you were IgG positive, IgM positive, or both IgG and IgM positive).
- Whether or not you received sufficient treatment for Lyme if you received positive test results in Canada.
- Whether or not your physician knew to test for a European strain of Lyme if you were bitten in Europe. If so, include the results.

Testing and Consultations - Out-of-Pocket

- Any out-of-country tests for Lyme that you have paid for (for both Lyme and its co-infections). For example, IGeneX tests. Cost of test, and the results that you received. Tell them why you opted to be tested elsewhere at your own expense.
- If your test result was positive according to CDC criteria (for example, IGeneX test results differentiate between their own criteria and that of the CDC) be sure to include that fact!
- If you were diagnosed by a non-Canadian physician, this is critical to include.
- Some patients are diagnosed by naturopaths in Canada. If so, be sure to mention that.
- Any other tick-borne co-infections that you have been diagnosed with, and if you have had positive Ontario test results for these co-infections.

Finding a Diagnosis

- Any tests, scans, surgeries, and/or hospitalizations you have had while searching for a diagnosis.
- Any misdiagnoses you have received by Canadian physicians.

- If you have been seen by an Infectious Disease doctor in Canada and whether they did or did not diagnose you with Lyme.

Treatment

- Any treatment you are receiving (or have successfully received) from a Canadian naturopath or an out-of-country physician.
- If you were offered appropriate treatment options by a Canadian MD once you had a diagnosis from an ND or MD outside the province (if the answer is "No" here, that is important!).
- If you have had improvement with treatment, *definitely* state that!

Impact

- The impact that the lack of education about this disease (and therefore your inability to receive timely diagnosis and treatment) has had on your life. For example, if you have been unable to work or attend school.
- Out-of-pocket costs for your diagnosis and treatment.
- The effect that this has had on you personally and on your family.

If you have any questions about writing your patient statement, please feel free to e-mail us at contact@ontariolymealliance.ca.

Please share this call for letters with anyone else you know who is affected by Lyme disease!

Yours sincerely,

The Members of the
Ontario Lyme Alliance

<http://www.ontariolymealliance.ca>