

**Public Health Agency of Canada**  
**Lyme Patient Round Table September 13, 2017**  
**Questions for Discussion**  
**Sept 12, 2017**

**PHAC Questions & Patient Responses:**

**GUIDELINES AND BEST PRACTICES**

1. *The Public Health Agency of Canada is considering sharing best practices on prevention, awareness and detection of Lyme disease. Are you aware of any innovative approaches and best practices in Canada or internationally that would benefit Lyme disease patients across Canada?*

**Patients' Response:**

- a. Patient oversight committee: A broad range of stakeholders must be permitted to participate in the development of the action plan for the Federal Framework. Specifically, there needs to be patient/patient group participation as well as participation by treating clinicians (those who have practices where they see Lyme patients at all stages of the disease), researchers who are studying ticks/tick-borne illnesses and other healthcare providers who support Lyme patients. Two examples of this type of comprehensive stakeholder involvement are already in place elsewhere. The Tick-Borne Disease (TBD) Working Group (mandated by the 21<sup>st</sup> Century Cures Act) is presently in ongoing meetings in the USA with patient group participants and treating physicians as members of the group. France is also working on developing a tick borne disease framework and patient groups and treating physicians are at the table there.
- b. Acknowledge ILADS as professional medical organization that is helping improve patients quality of lives – there needs to be acknowledgement in the Framework that the International Lyme and Associated Diseases Society (ILADS) 2014 Lyme Disease Treatment Guidelines have been endorsed by the Institute of Medicine and listed on the National Guidelines Clearinghouse as evidence-based, peer-reviewed and trustworthy.

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- c. Educate the public and medical professionals as to the existence of the ILADS guidelines which are more up to date treatment than the 2006 IDSA guidelines as per the recommendations of Drs Gregson and Quach, past presidents of the AMMI, in their letter to the editor CMAJ Aug 22, 2016 where they stated *“Until the updated IDSA or National Institute For Health and Care Excellence Lyme Guidelines are available. We recommend physicians use treatment guidelines as found in traditional sources such as reviews in high-quality journals, expert consultation, DynaMed, Up To Date, or evidence from clinical trials in the medical literature.”* These guidelines should be recognized as best practices.
- d. Evaluate new testing technology options that are showing greater sensitivity and specificity than current two-tier testing. Examples: Using the Elispot & C6 Elisa in parallel would yield 93% sensitivity and 95% specificity with a false positive rate of 7%. This is technology already available and being used in Canada. Also evaluate urine / nanotrap testing, and bio-marker testing. There are papers that describe EliSpot, Nanotrap, and metabolomic approaches. How are you are intending to evaluate these - or any - new diagnostic techniques for their performance in suspected CLD/PTLDS?
- e. It would be highly beneficial if physician education properly identified the signs and the symptoms of Lyme disease. Knowing the objective signs of a disease helps a physician better determine a clinical diagnosis. Presently, most literature does not differentiate between the signs and the symptoms of Lyme disease. When testing is as unreliable as it is for Lyme disease, physicians need this information.
- f. Include patients’ experts (i.e., Canadian Lyme Science Alliance, Canadian treating clinicians) that are currently being left out of the development of the framework action plan.
- g. It is time for the medical community to put any biases aside and work together with each other, encompassing public health, family doctors, infectious disease consultants, Health Canada, people who have Lyme and

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their caregivers, to resolve the many conflicting opinions with regards to treatment and diagnosis of this potentially most debilitating illness.

**2. *In anticipation of the public launch of the Lyme Disease Research Network Request for Applications:***

**A. *What researchers/research groups are patients already connected with?***

**Patients' Response: Patients' Response:** It is not clear to the patients/the public what the Lyme Disease Research Network is. In the spirit of transparency which was emphasized at the Conference, it would be helpful to know who the members are, how and by whom were they chosen. How do interested and qualified researchers (ie., Canadian Lyme Science Alliance, G. Magnotta Lab at University of Guelph, Mount Allison University Tick Research Centre) join this network?

**B. *Where do you see opportunities for strengthening connections with the Canadian Lyme disease research community?***

**Patients' Response:**

- i) Greater transparency on what this network is doing; who is setting priorities?
- ii) Create mechanism for patient input into research priorities;
- iii) Establish the oversight committee referred to above;
- iv) Include all qualified and interested scientific partners

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**SURVEILLANCE**

3. *We will be working to explore the epidemiology and trends of people who do not meet the current case definition. We are also planning to perform an analysis of the costs associated with Lyme disease.*
  - a. *Are you aware of any data/work that the Agency could build on and any suggestions on how this work could proceed?*

**Patients' Response:**

i.) Full economic analysis is needed including disability costs (CPP + private insurer claims), lost income, lost productivity, future opportunity costs, ongoing costs to medical system, lost tax revenue, social cost; etc. It also should capture the costs arising from people becoming afraid to enjoy the outdoors due to the growing risk of infection from tick bites and the known challenges people currently face in obtaining an early and accurate diagnosis and sufficient treatment. The Northeast USA is feeling the impact of this as outdoor-related businesses, tourism and the economy are already experiencing financial losses.<sup>1</sup> There should be action on the data in some fashion to improve patient outcomes. What is your strategy to translate their findings to the clinic?

ii.) Some American studies were drawing on large numbers of people – 52,000 people studied in that one paper. Our numbers are less than 1,000 per year – need a work around so therefore must be clinical; if we stick to current restrictive definition which was designed for epidemiology purposes it will miss majority of cases; therefore need to engage practicing / retired clinicians like Dr. Zubek, Dr. Cormode, Dr. Hawkins to develop a working case definition and develop a survey to start capturing relevant and robust statistics

iii.) In the Framework, it speaks to collection of data on alternate cases. What is PHAC's plan to collect this without changing case definition, and given that if Doctors treat based on an EM rash and/or clinical signs or

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<sup>1</sup> <http://environment.yale.edu/news/article/ecosystem-disservice-lyme-disease-imposes-large-cost-on-the-northeast-united-states/>

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symptoms, they will likely not report since the test (if done) won't be accurate until after early treatment commences?

iv.) What steps are being taken to collect existing vet data?

v.) Refer to following literature: 1) John Hopkins study showing treatment failure<sup>2</sup>, 2) Netherlands study showing cost<sup>3</sup>, 3) Ogden et al paper showing that as you go from east to west, testing becomes less reliable because of genetic diversification of the organism.<sup>4</sup>

vi.) Use and build on existing survey data: Manitoba Lyme Survey and LymeHope's March 2017 National Benchmark Survey. Also, can you please confirm that Lyme and post Lyme chronic cases will be included in the Canadian Community Health Survey?

*B. What would you see being done with this information once collected?*

**Patients' Response:** This information should be shared transparently and in a timely fashion with all Lyme stakeholders including patient groups and advocates

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<sup>2</sup> <https://www.jhsph.edu/news/news-releases/2015/lyme-disease-costs-more-than-one-billion-dollars-per-year-to-treat-study-finds.html>. On CanLyme's website: "This study has limitations as noted therein and does not include (a) cost of taxpayer funded disability income payments to the chronically ill, (b) loss of taxable income from those who are unable to work, (c) loss of productivity in the employment sector, (d) along with other indirect costs to society and the taxpayer. It also does not reflect those infected with a Lyme disease bacteria not detectable using current CDC/IDSA protocol other than the estimated figures which many say are under estimated at least 3 fold."

<sup>3</sup> An abstract is linked in the official message on their website but access to the full paper is restricted. [http://www.rivm.nl/en/Documents\\_and\\_publications/Common\\_and\\_Present/Newsmessages/2017/Lyme\\_disease\\_costs\\_EUR\\_20\\_million\\_annually](http://www.rivm.nl/en/Documents_and_publications/Common_and_Present/Newsmessages/2017/Lyme_disease_costs_EUR_20_million_annually). There were a couple of older studies on the costs of LD done in the States but they date back to 1998 and 2006.

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pubmed/28182723>

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**EDUCATION AND AWARENESS**

4. *The Public Health Agency of Canada will be working with health professional associations to develop tools to raise awareness of Lyme disease, in particular, to assist front-line health professionals and public health authorities in the prevention, awareness, and detection of Lyme disease. We will also be working with partners to develop education and awareness campaigns for the public and specific high-risk groups.*

a. *What role are patient groups currently playing in Lyme disease education and awareness of health professionals and the public?*

**Patients' Response:** See summary of Provincial Groups in Introduction document. Why are patients doing this work, and have been for the last 30 years? How can you have education without the proper foundation of information (selective science, ILADS guidelines and research being excluded). IDSA guidelines are outdated and stand in the way of providing accurate information – relying on them jeopardizes all three pillars

b. *What specifically would you want to focus on for front-line workers when they see suspected/probable Lyme disease cases or Lyme disease patients?*

**Patients' Response:**

- i) Education and photos showing multiple manifestations of EM rashes; not just the “bullseye” form.
- ii) Education on how to recognize symptom clusters and how to make a clinical diagnosis; limitations of current testing
- iii) Encourage medical professionals to be aware of ILADS treatment guidelines and to understand different cases require different

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treatments (attached tick – time unknown, vs. EM rash (early dissemination) vs. clinical signs and symptoms suggesting late stage disseminated tick-borne disease).

- iv) Stop recommending “prophylactic dose”. It may suppress the EM rash (but not necessarily cure the disease) making it harder to diagnose, and under treatment in those who are infected could lead to antibiotic resistance within our vast microbiome much of which is released back to nature through urination and defecation. Because this issue is a broad public health matter it falls within the mandate of Health Canada. Prophylactic dose is not recommended by ILADS<sup>5</sup> due to a) the lack of high quality evidence to support its effectiveness, b) evidence showing treatment of under 20 days leads to a high treatment failure rate, and c) weighing the possible risk to patient of long term chronic and disabling disease vs. risk of several weeks of antibiotic treatment clearly supports a more cautious approach to protect patients
- v) Collaborate with Provincial and Regional health units to ensure consistent messaging and advice on websites and in literature.
- vi) Encourage medical professionals to report ALL suspected case

a. *Which health professional groups should be targeted as a priority?*

**Patients’ Response:** Family physicians and Emergency Room staff as they are usually the first contact with infected patients. Followed by specialists that will commonly see possible Lyme patients due to common symptoms (ie. Neurologists, mental health, rheumatologists, cardiologists, pain specialists)

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<sup>5</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4196523/>

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*c. Who should be the focus of the public education campaigns?*

**Patients' Response:** Highest risk groups are adults over the age of 50 / retirees, children, outdoor enthusiasts, outdoor workers, military and indigenous populations. Therefore, targeting these groups should be the priority (retirees, parents, outdoor enthusiasts and indigenous populations).