

Collective Patient Group Response to PHAC’s call for input on their Lyme Disease Web Optimization 2020 sent as an email to Steven Sternthal, Director, Public Health Agency of Canada, Kim Elmslie, Vice-President, Infectious Disease Prevention and Control Branch, PHAC, and cc’d PHAC secretariat on September 11, 2020.

Dear Steven and Kim:

We have carefully reviewed the revisions that are proposed for the PHAC Lyme disease webpages. The attached document provides our recommendations in full detail. However, some of the issues we would like to specifically address follow.

Ongoing Downplaying of Lyme disease as a Potential Diagnosis

Canadians have always found it challenging to find physicians who know to make a clinical diagnosis of Lyme disease. This is in large part due to the fact that Lyme disease has been downplayed in public health messaging for so many years that the misinformation that “Lyme is rare in Canada” is now firmly entrenched in the healthcare community. The authors of the paper, “[Under-Detection of Lyme Disease in Canada](#)”, revealed the severity of under-detection of Canadian cases. Those patients who are not being diagnosed and treated appropriately early often succumb to severely debilitating and persisting symptoms of Lyme disease. The Canadian patient experience was studied in “[Motivations and Experiences of Canadians Seeking Treatment for Lyme Disease Outside of the Conventional Canadian Health-Care System](#).” Among the issues identified is that the Canadian healthcare system has been utterly failing desperately ill Lyme patients for years. Canada has unwittingly developed a two-tier healthcare system that resembles the American model at its worst. Lyme patients, who have the needed financial resources, are being compelled to pay out-of-pocket to buy access to the care and treatment they need. Financially strapped Lyme patients are abandoned and become pariahs in the Canadian healthcare system. We all have a moral obligation to rectify what is clearly a violation of every Canadian’s right to access the healthcare they need.

Neglecting to Include All Tick-borne Pathogens

While the inclusion of three other tick-borne pathogens to the healthcare providers’ Lyme disease webpage is a good step forward, there are numerous other tick-borne illnesses that need to be added to that list. Fifteen tick-borne pathogens of concern are listed in your own Canada Communicable Disease Report (CCDR) Volume 45-4, April 4, 2019: [Climate change and infectious diseases: The challenges](#). Healthcare provider and public awareness of all these illnesses and the tick species that carry them is critical as is physician education related to diagnosis, testing and treatment of each illness. We propose that the webpages, both public and healthcare provider, show due diligence in mitigating the known health risks by addressing all tick-borne diseases.

There is no reference to the fact that research has determined that ticks frequently carry multiple pathogens which are known as “co-infections”. Often, the severity and complex symptom presentation of a Lyme patient are attributable to co-infections.

Inadequate Addressing of Lyme Disease and Pregnancy

The proposed revisions fail to adequately address Lyme disease in pregnancy and mother-to-baby transmission. Therefore, we have supplemented the content with further information.

Inappropriate Promotion of Case Definition as a Basis for Diagnosis

It is very disconcerting to find ourselves correcting the “Lyme Disease Web Optimization 2020” document more than once where the case definition is erroneously used to advise health care providers of the criteria needed to make a clinical diagnosis. An example taken from your proposed revisions says: “*A patient presenting with an erythema migrans may be clinically diagnosed with Lyme disease, if they have a history of exposure. That is, if they live in an endemic area or have recently travelled to an area where infected ticks are prevalent. In this instance, treatment is recommended.*” Clearly, this is case definition criteria which applies only to the reporting of cases to public health and not to the diagnosis of a case. Reference to the Centre of Effective Practice’s [Early Lyme Disease Management in Primary Care Tool](#) is essential in the health care provider’s information.

Misrepresenting Late-stage Lyme disease and Symptom Persistence

Your draft version lacks a balanced perspective about the patient experience of those suffering with late-stage Lyme disease and persisting symptoms. The CDC acknowledged in the past that at least 10 to 20% of patients do not find their symptoms fully alleviated after having followed the IDSA treatment protocol. While the 2006 IDSA Lyme Treatment Guidelines deny these patients further treatment, the 2018 NICE Lyme Disease Guidelines advise a second course of treatment in these cases. As well, the 2014 ILADS Lyme Disease Guidelines recommend further treatment in order to better ensure the eradication of the bacteria. Those who do manage to obtain a Lyme diagnosis, often find themselves denied further treatment should their symptoms not be alleviated after the recommended IDSA course of treatment. Post treatment Lyme disease syndrome (PTLDS) is the IDSA’s label for persistent symptoms of late-stage Lyme disease. It is a highly offensive term to patients because it has been used as a tool to stigmatize and marginalize patients and diminishes the real harm done to all those suffering with persistent symptoms of Lyme disease. Millions globally have been labelled with this term, PTLDS, and tossed to the street. The experience of many Canadians is that they have been unable to find a physician capable/willing to make a Lyme diagnosis and provide needed treatment over an extended period of time (months to decades) following one or more infected tick bite(s). Ever-increasing numbers of Canadians are becoming severely debilitated and left to suffer the multi-systemic complications of late-stage Lyme disease. The IDSA has never made any effort to address the suffering and says only that this cohort is misguided in their suspicion of Lyme disease and needs to work harder at finding an alternate cause for their symptoms.

Inappropriate Removal of ILADS Guidelines

We are completely opposed to the proposed removal of the link to the ILADS Lyme Disease Treatment Guidelines in the healthcare provider webpages. The proposal that treatment guidance would be singularly linked to AMMI is highly inappropriate. As we have noted and emphatically stated at the PHAC Lyme Disease Multi-disciplinary Stakeholder Roundtable meetings, the singular endorsement of the 2006 IDSA Lyme Disease Treatment Guidelines in Canada has little to do with what is referred to as best practices. Two lawsuits have been filed against the IDSA and the key authors of the IDSA Lyme guidelines and in the more recent lawsuit, eight American insurers are also implicated. That these guidelines are deemed “best practices” with lawsuits alleging “antitrust” and “corruption and racketeering” raises questions about motives behind the endorsement of these guidelines.

A new version of the IDSA Lyme Disease Treatment Guidelines is pending; however, it promises to exacerbate the issues and the patient harm further. One year ago, eighty-seven Lyme organizations from the US, Canada, Australia, France, Germany, the U.K., the Netherlands, Belgium, Latvia, Spain and Poland co-signed [The Ad Hoc Patient and Physician Coalition Comments of the IDSA Proposed Lyme Guidelines](#). The quote below succinctly summarizes the reasons why patients, advocates and treating physicians are outraged by the proposed IDSA Lyme Guidelines.

“A number of the recommendations in the proposed guidelines will be regarded as completely unacceptable to the stakeholders most affected by these guidelines, the patients and the physicians who treat them. Chief among these are a) the decision to exclude from the panel representative patients and their treating physicians, b) the failure to consider patient-important outcomes, values and preferences, c) the failure to provide for the exercise of clinical judgment and consideration of patient values and circumstances or individualized care for patients, d) the failure to diagnose patients who do not live in endemic areas, e) the failure to diagnose patients with non-specific symptoms, e) the failure to provide an adequate duration of treatment for those diagnosed early to assure cure, f) the failure to provide any opportunity for retreatment for patients who fail an initial course of antibiotic treatment, and g) the failure to consider the devastating consequences to patient lives that these guidelines will cause.”

The issue of treatment guidelines for Lyme disease has become polarized with mainstream medical bodies callously ignoring the plight of millions of patients worldwide who suffer because they are denied access to the care and treatment they need. The IDSA Lyme Treatment Guidelines utterly abandon patients and tie the hands of their physicians. As the prologue to MP Elizabeth May’s [Bill C-442](#) which was enacted in December of 2015 says in reference to the IDSA Lyme Treatment Guidelines:

“the current guidelines in Canada are based on those in the United States and are so restrictive as to severely limit the diagnosis of acute Lyme disease and deny the existence of continuing infection, thus abandoning sick people with a treatable illness;”

The mandate of the legislation was for the IDSA Lyme Guidelines to be replaced with guidelines developed for Canadians with Canadian patients, researchers, clinicians at the table. Instead, the same IDSA guidelines identified as abandoning patients were rolled out again as “best practices” in the 2017 federal Lyme framework which was written by undisclosed authors with no stakeholders involved in the final decision-making.

The legislation also calls for a review of the present federal framework to be tabled by the Minister of Health no later than May 2022. To date, you have not provided any assurance that patients, advocates, caregivers, clinicians, healthcare providers, researchers and other stakeholders will be given an equitable voice and full participation in upcoming review of the framework.

Until such time as a full and transparent review of the framework is undertaken, we ask that in the best interests of Canadians, the link to the ILADS Lyme Treatment Guidelines remains on the PHAC healthcare provider webpage. As we and others have argued at the roundtable meetings, treatment decisions for individuals presenting with Lyme disease should be turned back over to our physicians with no obstruction to their access or use of either the IDSA or the ILADS Lyme Guidelines. Treatment guidelines are just that,

guidelines not regulations. They exist to provide physicians with guidance not as a tool to enforce a political agenda.

The authors of the recently published paper, [Lyme Disease Patient Outcomes and Experiences; A Retrospective Cohort Study](#), undertook a study to determine the responses of Canadian Lyme disease patients with a clinical diagnosis of chronic Lyme disease to a treatment regimen based on ILADS treatment guidelines. The authors state: “We find that the majority of patients responded positively to treatment and a significant ($p < 0.05$) decrease in symptoms was observed over time.” These findings present another very strong argument for a link to the 2014 ILADS Lyme Disease Treatment Guidelines to be included on the PHAC Lyme disease health provider’s webpage.

We are vehemently opposed to a singular link to AMMI being provided for treatment information and insist that in the best interests of our physicians and Canadians that a link to the International Lyme and Associated Diseases Society also be provided for treatment information.

Next Steps

Your email provided no information on the next steps in the development of new webpages. We would like to be involved in the discussions pertaining to the decision-making and finalizing of the webpages. As key stakeholders who represent Canadians living with Lyme disease, we believe we should be involved and trust you agree. We look forward to your reply.

Regards,

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