Sample letter re Lyme Disease

April 2016

The Honourable Jane Philpott, PC, MP

Minister of Health

House of Commons

Ottawa, ON K1A 0A6

Dear Minister:

Canada is about to embark on developing a national framework for Lyme disease, but utmost care will need to be taken to provide transparency and a balanced viewpoint so that the framework is not influenced by bias. The legislation, Bill C-442, assigns you, as Minister of Health, full responsibility for developing the framework and for writing a report to Parliament. It appears that once the national conference is over, any participation by patients and their experts ceases. This will mean that there is no mechanism in place for fair and equal representation of the patient in the actual development of the framework, and once again, that responsibility will be ceded to a strictly political and bureaucratic process.

For decades, Canadian Lyme patients have been denied access to sufficient antibiotic treatment due to a very restrictive set of treatment guidelines written by the Infectious Diseases Society of America (IDSA) and endorsed by the Association of Medical Microbiologists and Infectious Disease of Canada (AMMI of Canada).  Treatment failure and patient harm have resulted.  In order to regain a good quality of life, thousands of Canadian Lyme patients have had to resort to paying out-of-pocket for American healthcare. Several thousand more patients do not have the ability to pay for American healthcare, and having no treatment options here, they are forced to suffer the severe debilitation of late-stage Lyme disease. Fatalities have resulted.

The National Guideline Clearinghouse (NGC) is an American government institution relied on internationally as a trusted source for treatment standards.  The 2006 IDSA Lyme Disease Treatment Guidelines were delisted from the NGC in January 2016 because the authors failed to meet a mandated review deadline. The IDSA has acknowledged that it will take two to five years for all the evidence-based research to be reviewed and a new guideline prepared. It is important to know that several of the authors, who will once again be writing the new set of guidelines, have long lists of conflicts of interest. Are you aware that the Attorney General of Connecticut charged the authors of the IDSA Lyme disease Treatment Guidelines with conflicts of interest in 2008?

With their removal from the NGC, the 2006 IDSA Lyme disease Treatment Guidelines are now outdated and fail to be a trusted source of treatment standards. Yet all of our federal, provincial and municipal government websites (and literature) on Lyme disease continue to cite the IDSA guidelines!

When Canadian patients resort to paying out-of-pocket for treatment in the United States, they consult with physicians who are members of the International Lyme and Associated Diseases Society (ILADS).  The 2014 ILADS Lyme Disease Treatment Guidelines have been listed on the National Guideline Clearinghouse since September 2015.  Before being listed on the NGC, the 2014 ILADS Lyme Disease Treatment Guidelines had to pass a very strict set of criteria developed by the Institute of Medicine which proves them to be up-to-date, trustworthy, evidence-based and reliable. Months after their NGC listing, there is still no government Lyme disease webpage/literature in Canada that refers to the 2014 ILADS Guidelines as a source of information for physicians.

Knowing that volumes of the most up-to-date, evidence-based research was reviewed in the preparation of the 2014 ILADS Guidelines, why has the AMMI of Canada not endorsed the 2014 ILADS Lyme Disease Treatment Guidelines? Are they still firmly holding on to the IDSA dogma and resistant to change?  We believe this is the case and this does not give us confidence that the federal Lyme disease framework will be written without bias.

When the Planning Committee for the National Lyme Conference met on January 29, 2016, PHAC's summary of the replies received in their June 2015 online consultation on Lyme disease was reviewed. Some members of the committee expressed concern that bias had been shown in PHAC's summary of the replies. The quote below comes from the [January 29th Planning Committee Meeting](http://www.healthycanadians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/lyme/federal-framework-conference-cadre-federal/meeting-january-29-janvier-2016-reunion-eng.php) summary.

"*Some planning committee members raised concern about:*

* *a disproportionate emphasis placed on reporting feedback from the comparatively small percentage of health professionals who responded*
* *the context given in the report seemed to be reiterating the status quo with regard to the current use of clinical guidelines from the Infectious Diseases Society of America."*

As a result, the Planning Committee decided an "outside contractor" will need to be hired to do further analysis of the data and to compile a summary for the Committee. It must be ensured that this individual is impartial. Clearly, it would be a conflict of interest for this person to be selected from the list of freelancers who rely on income acquired through PHAC contracts.

The Institute of Medicine (USA) now requires that the key stakeholders, the patients, participate in the development of all treatment guidelines. Therefore, the development of our Canadian framework should follow the same principle, but currently there is no provision for patients and their advisors to have oversight in the writing of Canada's Lyme disease framework. The Canadian Lyme Disease Foundation is a partner in the planning of the National Conference, and it would be appropriate for CanLyme (and its advisors) to be a partner in the development and writing of “the report that sets out the federal framework” for Lyme disease.

Minister Philpott, will you provide for patient representation as well as transparency and oversight in the development of the federal framework for Lyme disease including the report to parliament? I look forward to your reply.

Yours sincerely,

*Your Name*

*Your Address*