Hello Dr. Tam and Dr. Mithani, October, 25, 2017

Thank you for your response to us dated September 29, 2017 acknowledging receipt of the Lyme Letters we delivered to the Health Minister in August 2017.

We look forward to more conversations as you suggested.  Canadians coast to coast are becoming increasingly alarmed about the risk to them and their families, and more and more people are reporting tick bites, infections and a very troubling shared experience in our medical system of dismissal, denial and lack of appropriate care and treatment.

We would like to share some exciting news about our **upcoming LymeHope event on November 3rd in Oakville, Ontario from 7-9:30pm – “Lyme Disease in Canada”.**  This panel discussion has been designed for medical professionals and members of the public who are interested in hearing from front-line Canadian physicians as well as two of Canada’s Lyme scientists.  The full list of speakers and topics can be found on the flyer attached as well as through our website.   Info and RSVP info can be found on our website including our downloadable flyer: <http://www.lymehope.ca/events.html>

If by chance you will be in the Toronto area on Nov 3rd, we would of course be honoured to have either or both of you, or members of your staff attend the event.  There is a lot of interest in this event and we are expecting a very good turnout.

At the upcoming event, I will be speaking and presenting on Lyme and Pregnancy/Transplacental transmission, which is very timely given that the Agency is currently working on a literature review on congenital Lyme disease.  I am also a Registered Nurse by background, trained at McMaster University, my nursing experience in the ER as well as community case management.  I truly value my training which certainly prepared me with a strong foundation of problem-based learning, seeking meaningful rationale to complex issues and of course being guided by evidence-based science.

I have recently reached out PHAC to request the opportunity for my involvement in this literature review, as I have personally researched and compiled literature on this topic including case reports, case series, pathology reports and other medical reference based materials.  Dr. Tam, can you *please confirm* that the literature I gave to you at our August 22nd meeting will be included in the review including the bound volumes of articles including the 5th edition (2001) of Remington and Kleins Infectious Diseases of the Fetus and Newborn Infant.

As I reflect on the importance of patient collaboration and engagement, I want to share with you a recent CMAJ editorial published on October 3, 2016 which I found particularly insightful.   Deputy editor Kirsten Patrick wrote about the importance of patient-relevant research and I quote, ‘For each step in the research process, investigators need to consider how to best involve patients in planning and decisions.  For patient-relevant research to be meaningful, patient and public engagement in research *cannot comprise a token lay person* on a research ethics review board.  Patients and their caregivers *must be involved in decision-making at all steps* in the research process, from design to choice of primary and secondary outcomes, through dissemination and implementation.’[1]

We trust that you will be supportive of our proposal to work alongside PHAC in the literature review as it is a perfect opportunity to enable the type of patient engagement you support in your response letter, as well as was emphasized at the recent Agency patient round table on September 13, 2017.   We think this literature review is a wonderful example of “low-hanging fruit” with opportunity for near-term action and education.

We would also like to share the recent Macleans article featuring LymeHope and our meeting with Minister Philpott and Dr. Tam.  This article highlights the role of patient advocacy which we believe is so important when it comes to Lyme disease.

[http://www.macleans.ca/society/health/how-the-new-impatient-patient-is-disrupting-medicine/](http://www.lymehope.ca/advocacy-updates/how-the-new-impatient-patient-is-disrupting-medicine)

We look forward to continuing the discussion and would like to **request a follow up meeting with you both**.  We are happy to return to Ottawa and hope that you will be able to schedule something with us soon.

Thank you again for your leadership and commitment to patient engagement and to working quickly to implement some concrete changes that will help all Canadians at risk for, and suffering from, Lyme & related diseases.

It is our desire to continue to build bridges and facilitate meaningful change and action to support Lyme sufferers and to provide opportunities for education, awareness and collaboration within the medical/allied health care/government and policy sector.  I believe we all want what is best for Canadians!

We look forward to hearing back.

Warmly and *with Hope,*

Sue Faber, RN, BScN & Jennifer Kravis, BA, LL.B

Co-Founders

LymeHope

[www.lymehope.ca](http://www.lymehope.ca/)

[1] CMAJ 2016. DOI:10.1503/cmaj.161084  <http://www.cmaj.ca/content/188/15/1063.full>