

Dear Dr. Mithani, Dr. Tam, Dr. Njoo, Kim, and Kate,

We just wanted to reach out today and first of all, express our appreciation for the Systematic Review (SR) which was just published on November 12th, 2018 in the highly regarded peer reviewed journal, PLoS ONE.

In this publication, Public Health Agency of Canada scientists clearly acknowledge:

- 1:** transplacental (mother to baby) transmission of Lyme disease (*Borrelia burgdorferi*) as an alternate mode of transmission
- 2:** high risk of adverse outcomes as identified in meta-analysis - 50% of pregnancies where the mother had untreated Lyme disease resulted in adverse birth outcomes '*providing indirect evidence of an association between gestational LD and adverse birth outcomes.*'
- 3:** placenta positive cases (*borrelia* spirochetes found in placentas)

For colleagues who may not have had the opportunity to read this SR – the paper is here: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0207067>

Direct quotes from the SR include:

'Across cases, evidence that transplacental transmission of *B. burgdorferi* can occur was shown by testing the placenta (n = 11) and deceased fetal/newborn tissue (n = 18), **Table 3**. Adverse birth outcomes occurred in 4/5 placenta positive cases (2 stillbirths and 2 cases of respiratory distress that recovered), in 2/6 placenta-negative cases (one premature birth and one case reported as relapsing LD beginning at 3 months of age, and spirochetes were identified in one or more fetal tissues in 15/18 autopsies (**Table 2**).'

'There are examples among the 59 case reports included in this SR that suggested transplacental transmission occurs including 4 cases of infection in the fetus or newborn determined using relatively reliable laboratory diagnostic methods.'

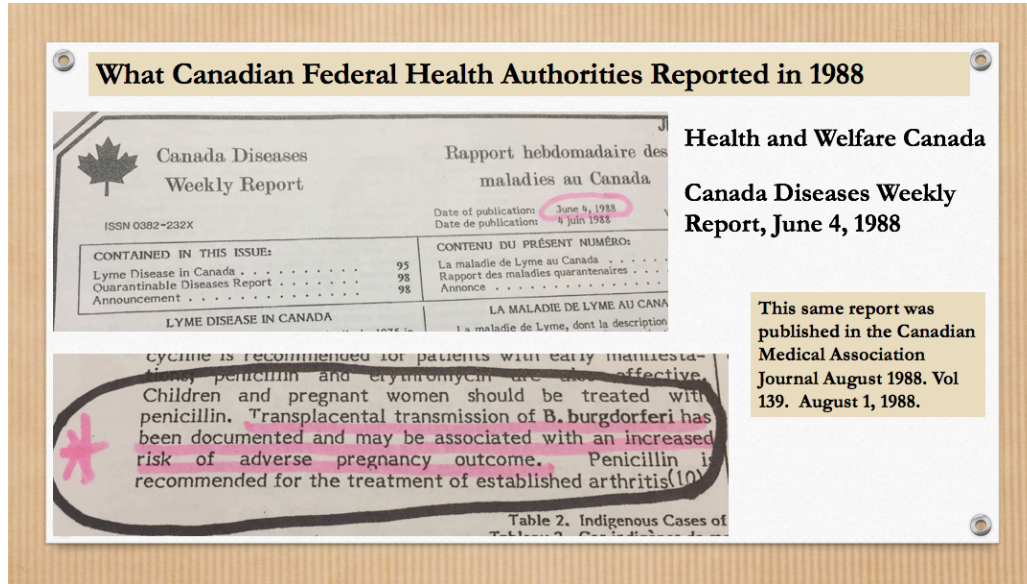
'This SR summarizes evidence from case studies that provide some limited evidence for transplacental transmission of *B. burgdorferi*.'

'A meta-analysis of nine studies showed significantly fewer adverse birth outcomes in women reported to have been treated for gestational LD (11%, 95%CI 7–16) compared to those who were not treated during pregnancy (50%, 95%CI 30–70) providing indirect evidence of an association between gestational LD and adverse birth outcomes.'

'Thus, the data suggest there is some evidence that adverse birth outcomes may occur more frequently if gestational LD is not treated.'

Systematic Review Findings Align with Important Publications and Announcements:

In 1988, Health and Welfare Canada first reported on transplacental transmission in their weekly report which had previously been reported in the Centers for Disease Control (MMWR - Vol 34, No 25, June 28, 1985).



Now, 30 years later, Public Health Agency of Canada has **once again** acknowledged the evidence that exists for in-utero/transplacental transmission and an 'indirect association between gestational Lyme disease and adverse birth outcomes' in your Systematic Review. This acknowledgement **must be accompanied by meaningful action** to help Canadian babies, children and adults who have been directly affected by this alternate mode of transmission.

RESEARCH ARTICLE

A systematic review on the impact of gestational Lyme disease in humans on the fetus and newborn

Lisa A. Waddell, Judy Greig, L. Robbin Lindsay, Alison F. Hinckley, Nicholas H. Ogden

Published: November 12, 2018 • <https://doi.org/10.1371/journal.pone.0207067>

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Adverse Outcomes:

"A meta-analysis of nine studies showed significantly fewer adverse birth outcomes in women reported to have been treated for gestational LD (11%, 95%CI 7–16) compared to those who were not treated during pregnancy (50%, 95%CI 30–70) providing indirect evidence of an association between gestational LD and adverse birth outcomes."

"Thus, the data suggest there is some evidence that adverse birth outcomes may occur more frequently if gestational LD is not treated."

Waddell LA, Grieg J, Lindsay LR et al. A systematic review on the impact of gestational Lyme disease in humans on the fetus and newborn. Plos One, Nov 12, 2018. <https://doi.org/10.1371/journal.pone.0207067>

In-utero Transmission of Borrelia burgdorferi

"Across cases, evidence that transplacental transmission of *B. burgdorferi* can occur was shown by testing the placenta (n = 11) and deceased fetal/newborn tissue (n = 18)"

"There are examples among the 59 case reports included in this SR that suggested transplacental transmission occurs including 4 cases of infection in the fetus or newborn determined using relatively reliable laboratory diagnostic methods."

"This SR summarizes evidence from case studies that provide some limited evidence for transplacental transmission of *B. burgdorferi*."

Q: When will PHAC and Health Canada issue a national press release to highlight the concerning results of your SR?

The findings in the SR are also complementary to the recommendation by authors of Remington and Klein's Infectious Diseases of the Fetus and Newborn Infant in each of its last three editions since 2001. Authors have included Lyme disease in their list of in-utero/congenital infections by recommending expansion of the well-known medical acronym for microorganisms that cause congenital infections, 'TORCH' to 'TORCHES-CLAP' with 'L' representing Lyme disease¹.

“TORCHES CLAP”

Table 1-4 Suggested Acronym for Microorganisms Responsible for Infection of the Fetus: TORCHES CLAP

T	Toxoplasma gondii
R	Rubella virus
C	Cytomegalovirus
H	Herpes simplex virus
E	Enteroviruses
S	Syphilis (Treponema pallidum)
C	Chickenpox (varicella-zoster virus)
L	Lyme disease (Borrelia burgdorferi)
A	AIDS (HIV)
P	Parvovirus B19

Authors suggest expanding the well recognized acronym TORCH to TORCHES CLAP, L= Lyme Disease

Once again, in-utero transmission of Borrelia burgdorferi recognized.

Despite these limitations, *B. burgdorferi* can cross the placenta, presumably during a period of spirochetemia. The frequency and clinical significance of transplacental transmission of *B. burgdorferi* are unclear. Although a temporal relationship between Lyme disease during pregnancy and adverse outcomes has been documented, a causal relationship has not been established. Claims for the existence of

The SR findings are also consistent with a response by the High Council of Public Health in France to members of the French National Assembly in July 2018, where it was clearly stated on public record that 'maternal-fetal infection is possible'.

NATIONAL ASSEMBLY

Since January 2017, the Ministry of Health has put in place a plan to fight against Lyme disease and other pathogens transmitted by ticks. The goals of this plan are to strengthen prevention, improve and standardize patient care by updating recommendations, and to organize specialized consultations for patients with tick-borne diseases. The High Health Authority has already published recommendations of good clinical practice allowing all doctors to take care, in a harmonized manner on the national territory, the different forms of the disease. The Directorate-General for Health (DGS) works, in conjunction with the regional health agencies, setting up specialized centers for the care of patients; Practitioners from these centers will participate in the initial and ongoing training of health professionals. The High Council of Public Health (HCSP), seized by the DGS, has already decided on the risks of transmission of the disease: in general, no transmission through breast milk, sexually or via products blood and transplantation is currently documented in human. Maternal-fetal infection is possible, and HCSP recommends antibiotic treatment for pregnant women with a diagnosis of Lyme borreliosis. Surveillance of the geographical distribution of the disease continues, with the epidemiological work of the National Public Health Agency (ANSP) and the internet reporting application open to individuals. The ANSP notes an increase in 2016 in the early cutaneous forms of the disease (erythema migrans), with no increase or other forms or hospitalizations.

Question publiée au JO le : **06/03/2018** page : 1852
Réponse publiée au JO le : **24/07/2018** page : 6689

Response from the High Council of Public Health, France, July 2018.

'Maternal-fetal infection is possible, and HCSP recommends antibiotic treatment for pregnant women with a diagnosis of Lyme borreliosis.'

Retrieved from: <http://www2.assemblee-nationale.fr/questions/detail/15/QE/6138>

¹ Maldonado Y, Nizet V, O.Klein J, Remington J, Wilson C. Current concepts of Infections of the Fetus and Newborn Infant (Chapter 1). Found in Remington and Klein Infectious Diseases of the Fetus and Newborn Infant, 8th edition, 2016.

It is also important to note that the World Health Organization (WHO) first reported on transplacental transmission of Lyme in September 1986 (Wkly Epidem. Rec. - No. 39 - 26 September, 1986) and has now recently added Congenital Lyme borreliosis (a baby infected in-utero and born with Lyme disease) to updated ICD-11 codes. <https://www.lymehope.ca/news-and-updates/world-health-organization-recognizes-congenital-lyme-borreliosis>

The World Health Organization recognizes Congenital Lyme borreliosis and adds alternate mode of transmission to ICD-11 codes - 2018.

- ▼ 1C1G Lyme borreliosis
 - 1C1G.0 Early cutaneous Lyme borreliosis
 - ▶ 1C1G.1 Disseminated Lyme borreliosis
 - ▶ 1C1G.2 Congenital Lyme borreliosis
 - ▶ 1C1G.Y Other specified lyme borreliosis
- 1C1H Necrotising ulcerative gingivitis
- ▶ 1C1J Relapsing fever
- ▶ Other diseases due to chlamydiae
- ▶ Rickettsioses
- 1C40 Campylobacteriosis



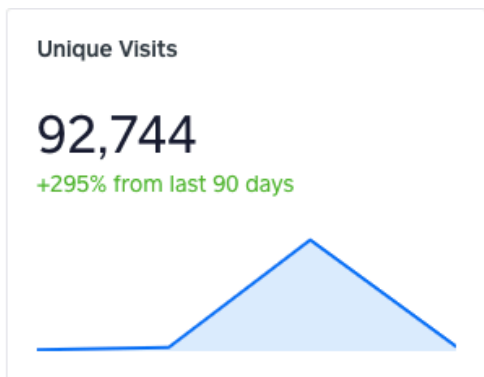
"The ICD is a product that WHO is truly proud of," says Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "It enables us to understand so much about what makes people get sick and die, and to take action to prevent suffering and save lives."

'Congenital Lyme borreliosis is an alternate mode of transmission of Lyme - from infected mother to her baby in-utero: thus the narrative transitions from a purely zoonotic disease (from tick to human), to one that can be transferred human to human, mother to child'.
- Sue Faber, RN - LymeHope

Collaboration and Partnership with PHAC appreciated:

This important acknowledgement of in-utero transmission and adverse outcomes indeed aligns with the dialogue we all shared from the October 5th, 2018 face-to-face meeting with you in Ottawa which we had highlighted in our LymeHope update. <https://www.lymehope.ca/news-and-updates/breaking-news-canada-acknowledges-maternal-fetal-transmission-of-lyme-disease>

The above post was viewed over 100,000 times through-out the world (attached a screen-shot of shared posts) and gave so many Lyme sufferers real **Hope** that eyes are opening to the devastating plight of entire families and children/babies infected with Lyme and co-infections.



Multi-disciplinary Round Table Identifies Maternal-Child Transmission as High Priority:

In June 2018, PHAC hosted an in-person Multidisciplinary Round table Discussion on Lyme Disease. This was attended by diverse representation of provincial and federal Public Health representatives, healthcare professionals, allied healthcare/veterinary, medical/nursing societies and associations and Canada-wide representation from patient advocacy groups and organizations. Invited participants were asked to choose topics that they felt were most important to address and **Maternal-Child Transmission was #2** on the list. This highlights the cross-Canada concern and support to address this alternate mode of transmission with urgency. The SR had not been published at time of this meeting.

<https://www.lymehope.ca/news-and-updates/public-health-agency-of-canada-multi-disciplinary-round-table-meeting-summary>

**Multidisciplinary Roundtable Discussion on Lyme Disease
Session Report**

5.2 Maternal-Child Transmission

5.2.1 Defining the Problem*

The following problem statements were put forward during the discussion:

- Women are unaware of the risk of transmission
- There is no standardized testing for Lyme disease during pregnancy
- There are no clinical practice guidelines despite a clear literature of evidence on trans-placental transmission
- Children are not being diagnosed for various reasons, including asymptomatic at birth, or multiple symptoms, or sero-negativity

5.2.2 Aspirational Reframing of the Problem

Statements that were proposed by participants included: *How might we ...*

- Prevent intra-placental transmission
- Better track children's medical history
- Identify how many women are affected

Tuesday, June 19, 2018
Lord Elgin Hotel, Ottawa

At the meeting participants individually selected two to four topics that they felt should be discussed during the rest of the day.

Maternal-Child Transmission was the second highest topic of interest selected by participants.

LymeHope Invited as Reviewers in the PHAC Systematic Review:

We are also thankful that given our expertise and interest in the subject matter, LymeHope was invited to review a draft copy of the SR in February 2018 and participate in a robust teleconference discussion with review authors and other stake-holders. We also were involved with several other in-person and phone meetings with PHAC executives to discuss our feedback in further depth. Based on the published version, it appears that many of our comments and recommendations *were indeed incorporated into the SR*. On June 15, 2018, in a written response to our review, we were told that authors were 'grateful for our comments'. It was also stated "The reviewers (Sue Faber and Jennifer Kravis) identified a number of areas and points that require further clarification or elaboration. We appreciate these being highlighted and we will work to address them in a revised version."

In the published SR, we did note that authors acknowledged PHAC librarians for their role. We are asking to be acknowledged as we invested significant time in our review and analysis to provide PHAC with meaningful, substantiated input which indeed was acknowledged and incorporated into the final Systematic Review. We believe that acknowledging the contributions of others is indeed the essence of scientific integrity, engagement and collaboration.

Q: How will PHAC authors officially acknowledge our participation, input and review of the draft which resulted in revision and changes?

As a result of the publication of the Systematic Review, we are respectfully requesting:

1: PHAC/Health Canada website updates:

We request that PHAC/Ministry of Health update your website section on Lyme and Pregnancy to clearly reflect the findings from your own SR including:

- clear acknowledgement in plain language of transplacental/in-utero transmission of *Borrelia burgdorferi* and risk of fetal infection.
- clear acknowledgement of the high risk (50%) of adverse outcomes in pregnancies with untreated Lyme as identified in your own meta-analysis.
- update your website under 'Causes of Lyme Disease' to ensure a clear description that Lyme disease *can be transmitted from a mother to her baby in-utero* resulting in fetal infection and congenital Lyme borreliosis (which has already been acknowledged by the WHO). This also means that the case definition of the disease changes from a purely zoonotic disease, to a disease which *can also be transmitted human-to-human*.

Q: When will these website updates be completed?

Q: How will frontline medical professionals and all Canadians be alerted to these updates and alerted to this alternate mode of transmission as well as risk of adverse outcomes?

2: Urgent Formation of a Federal Multi-disciplinary Task Force:

LymeHope respectfully requests that PHAC and the Honorable Minister of Health Ginette Petitpas-Taylor urgently form a Federal multi-disciplinary working group to specifically address in-utero transmission, adverse outcomes and congenital Lyme borreliosis. We believe this alternate mode of transmission not only impacts Canadians but has massive global implications.

The current case definition of Lyme disease must be re-examined and re-defined from a purely zoonotic disease (from the bite of a tick), to a disease which indeed can be transferred human to human (mother to baby). **This reality has paradigm shifting public health implications.** Public Health surveillance criteria must also be re-evaluated and updated to ensure that babies infected in-utero are counted and included in Canadian statistics.

As an aside, during the AIDS crisis, AIDS activists urgently called on the US Government to form a 'Manhattan Project for AIDS'. In 1990, an impassioned letter was published in the New York Times and authored by activist Larry Kramer. In his letter, he described the government's response to the crisis: 'Paths of least resistance are the chosen norm. Imagination is not encouraged, and exchange of vital information is often nonexistent'. He also stated: 'The armies of the infected, their families, loved ones and friends no longer know how to deliver their pleas for help' and 'The bureaucracy is so byzantine, nobody can or has to make a decision'. In his conclusion, Larry passionately stated, 'Only an all-out effort by the Federal Government can defeat AIDS. It alone it has the resources and authority to win.'
<http://movies2.nytimes.com/library/national/science/aids/071690sci-aids.html>

In 2014, US authors published an article calling for a "Manhattan Project" to combat the Lyme epidemic. <https://journals.plos.org/plospathogens/article?id=10.1371/journal.ppat.1003796>. We whole-heartedly agree that this type of approach is needed for Lyme disease. We need our Canadian Federal Government to take notice to *what you have now acknowledged in your own Systematic Review* and take urgent action.

The task ahead is daunting but as the Lyme epidemic grows and as this disease can be spread human-to-human, the reality is we cannot be passive and hope that this problem will fade away or defer responsibility to other groups and organizations to take the lead - we believe as the Public Health Agency of Canada, *it is your role and responsibility to facilitate this*. We need to work together, check our differences at the door, roll up our sleeves and get to work.

We believe that the purpose of this Federal multi-disciplinary task-force goes beyond the scope of the PHAC funded Society of Obstetricians and Gynecologists (SOGC) project. To our understanding, this project has plans to develop a National Survey and Needs Assessment for OB/GYN practitioners, a tool-kit, and a longer-term plan for development of clinical practice guidelines to treat pregnant women.

This funded SOGC/PHAC project is *indeed critically important* and we look forward to participation and collaboration with the SOGC, however, we must also focus on transmission to baby and significant public health implications of this documented reality – for those **currently infected** or babies who may be infected in the future. We believe that urgent qualitative and longitudinal research needs to be undertaken with families/mother-baby pairs who are self-identifying as all their children are sick with Lyme and co-infections.

We have already liaised with several Canadian and International medical professionals/scientists and other experts specializing in areas such as pediatrics, obstetrics/gynecology, midwifery, primary practice, pediatric infectious disease, Indigenous/Aboriginal health, cardiology, neonatology, epidemiology, biology and microbiology who are interested in participation and collaboration. Such an effort would indeed highlight Canada as a leader and global champion for change in this specific area. We also believe that Canadian Lyme sufferers with lived experience need to be actively engaged and valued in the entire process - from inception to completion, as they have first-hand experience and expertise. Their voice and guidance is crucial.

A multi-disciplinary team of this scope could review the nuances and important clues from historical literature including the extensive work of Dr. Tessa Gardner (Harvard trained Pediatric Infectious Disease Doctor) in the 4th and 5th edition of the world's most authoritative and renowned reference medical textbook - Remington and Klein's Infectious Diseases of the Fetus and Newborn.

A hard-copy of this textbook was given directly to the Parliamentary Standing Health Committee in Ottawa in June 2017 where I was called to speak as a witness and where I highlighted the urgency of re-examining in-utero transmission of Lyme. My testimony here: <https://youtu.be/-gByuqmZBNk>



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42nd Parliament, 1st Session (December 3, 2015 - Present)

FEDERAL FRAMEWORK ON LYME DISEASE

Last meeting: Thursday, June 8, 2017

June 2017 – Called as Witnesses to speak at Parliamentary Standing Health Committee



We believe that multi-disciplinary expertise coming together to review in-utero transmission and congenital Lyme borreliosis could cross-fertilize with expertise and lessons learned from other congenital infectious diseases such as syphilis, HIV and Chagas disease to name a few. This team could also identify research priorities and focus on developing a new case-definition for congenital Lyme borreliosis as it is obvious that babies infected in-utero would not have a requisite tick bite in an endemic area and babies would likely be seronegative by standard testing mechanisms as already identified in the historical literature.

Q: When will PHAC initiate a Federal Multi-disciplinary working group with LymeHope as an active partner to specifically focus on in-utero transmission and congenital Lyme borreliosis and tackling the significant public health implications to this alternate mode of transmission?

“Listen to your patient; he is telling you the diagnosis.” - Dr. William Osler



On August 22, 2018, we hand-delivered thousands of 'Lyme Letters' from Canadians to then Minister of Health Jane Philpott and Dr. Theresa Tam. These letters were written through the LymeHope sponsored Lyme Letters Campaign and personally addressed to Minister Philpott. Many of these hand-written letters were from families and individuals concerned about the possibility of in-utero transmission and pleading with the Minister of Health to take action and investigate their plight. Children wrote letters and colored pictures. The suffering, neglect, abuse, loneliness, marginalization and desperation amongst Lyme sufferers is clear, the lack of understanding and appropriate medical training with regards to this complex medical illness has resulted in many Canadians being denied care. Those with chronic disseminated, late stage Lyme are often dismissed and refused, many shared their experiences as being treated 'like a leper', an 'untouchable', or a 'maligner'.

Our journey to hand-deliver these letters as well as scientific and medical literature on Lyme and Pregnancy and congenital transmission of Lyme disease was highlighted in an article published in Macleans Magazine. <https://www.macleans.ca/society/health/how-the-new-impatient-patient-is-disrupting-medicine>

HEALTH

How the new impatient patient is disrupting medicine

Patient activists have never been as vocal. But are they truly being heard?

by Anne Kingston Oct 21, 2017



Jennifer Kravis and Sue Faber prepare for their meeting with the Minister of Health in Ottawa to discuss Lyme Disease. (Photograph by Jessica Deeks)

Minister Jane Philpott handed these letters over to PHAC and we were told in an official response from Dr. Mithani and Dr. Tam that these letters were 'illuminating and touching' and 'deepened our understanding of the challenges of Canadians with Lyme disease are confronting', and we were thanked for our important work to raise awareness and to support Canadians affected by Lyme disease.

We certainly appreciate this written acknowledgement of the thousands of letters but *what is urgently needed is action*. Action must be anchored in the narrative of Canadians who took the time to pour out their aching hearts, many telling us that they literally wept as they wrote their letter, praying that this time, there would be a miracle and you would listen and act.

To our understanding none of these letters were personally responded to by PHAC officials and they have since been stored in archives. The penned tragedies, heartache, pleading for recognition, desperation and **Hope** which many Canadians - young and old expressed, are sitting in some dark storage room or electronically scanned into some nebulous government folder. We must not ignore those who suffer and have reached out, begging for help.

We have asked on multiple occasions to personally meet with Dr. Theresa Tam (Chief Medical Officer for PHAC), as she also has training and back-ground in Pediatric Infectious Disease. We have also asked to personally meet with our new Minister of Health Ginette Petitpas -Taylor, so far these requests have not been accommodated and so again today we respectfully ask for these meetings.

**Q: When will LymeHope's meeting requests with Dr. Tam and Minister Petitpas-Taylor be granted?
Q: Will Canadians who wrote the Lyme Letters received by PHAC be acknowledged and receive a personal response?**

Excerpts from three 'Lyme Letters':

I am not writing this letter because I want to, or because I have any hope you, or anyone who could, might actually help us. Please, oh good gracious me, PLEASE PROVE ME WRONG. I am begging you.

all Canadians is protected, yet the current ISDA standards are still being held as a gold standard here and Canadians are not being treated adequately. I thank you for reading this and I beg you for your help – for my family, for thousands of families across Canada. We need your help. The political red tape over whose jurisdiction/responsibility Lyme Disease treatment, testing and training falls into needs to stop and we need to come together as a Nation and help Canadians NOW. Please help us.

LymeMoms live in a **constant state of terror and agony**, worrying about their children's future and whether one day their children will be able to get care at home, and whether they will die young or become crippled from neurological degeneration. LymeMoms stay up late researching on the internet, trying to become medical experts as best they can. LymeMoms live in fear that if they are seeking treatment for their children, they will be reported and investigated by child & family services. LymeMoms are routinely accused of Munchausen's by Proxy. LymeMoms who themselves have tick-borne disease wonder if they **infected their children during their pregnancies**, and worry if their grandchildren will also be born infected and doomed to a life of continuous suffering and loss.

LymeMoms fight tirelessly for themselves, their children, and all other men, women and children dealing with this horrific disease – **because no one else is.**

I am a LymeMom. This is our story.

Registered Nurses Association of Ontario (RNAO) Resolution on Lyme Disease:

As a result of reading through each and every letter and identifying common themes and concerns in the 'Lyme Letters' <https://www.lymehope.ca/lyme-letters-canada.html> as well as over 14,750 public petition comments through our Ticking Lyme Bomb Petition <https://www.change.org/p/minister-petitpas-taylor-ticking-lyme-bomb-in-canada-fix-canada-s-lyme-action-plan-now> and indeed the personal speeches from Lyme sufferers at the PHAC sponsored Federal Lyme Conference in June 2016, <https://www.lymehope.ca/lymevoice/federal-lyme-conference-may-2016-testimonies-from-canadian-patients> I collaborated with members of the Registered Nurses Association of Ontario (RNAO) to write a resolution on Lyme disease - 'Patient First Treatment of Ontarians with Lyme Disease'.

This resolution highlighted in-utero transmission of Lyme disease as well as many other serious concerns and issues expressed by Canadians. This resolution was carried on May 20, 2018 by RNAO membership. Later on, the RNAO highlighted my personal advocacy story and the Lyme resolution in its journal *Registered Nurse* which was broadly shared with membership and beyond. We are thankful to the RNAO for their on-going support. <https://www.lymehope.ca/news-and-updates/registered-nurses-association-of-ontario-rnao-focuses-on-lyme-disease>

Mothers concerned about In-utero Transmission of Lyme:

When it comes to in-utero transmission and congenital Lyme borreliosis, most moms we have spoken with including myself ***didn't have a tick-bite or EM rash and didn't have a diagnosis of Lyme prior to pregnancies*** and this reality is disturbing yet predictable. Many mothers were indeed asymptomatic, and if one explores other TORCH infections, namely syphilis (which is also a spirochetal infection), it is clearly highlighted that amongst women with syphilis, 'many do not have any symptoms or have only minor symptoms and do not realize anything is wrong.' It is also stated that 'latent syphilis infections in pregnancy result in serious adverse pregnancy outcomes in more than half of the cases.' (WHO Guideline on Syphilis Screening and Treatment for Pregnant Women, 2017).

Considering Lyme disease is also a spirochete, it would make sense that infection in pregnancy – whether untreated acute, chronic, reactivated latent, or latent infection, would have similar implications as syphilis, and indeed, the meta-analysis in the SR identified a startling rate (50%) of adverse outcomes in untreated women!

Symptoms Identified in Mothers:

Many of the mothers we have spoken with who have children they believe to have been infected with Lyme and co-infections at birth, have reported multiple miscarriages, some have reported stillbirths with unrevealing autopsies. Many report difficult pregnancies with hyperemesis, toxemia/preeclampsia, transient rashes, pre-term labor and more.

Symptoms Identified in Babies/Children born with Lyme disease:

After birth, we've heard from moms who report their babies dealing with respiratory issues, jaundice, rashes, pre-term birth, some babies very sick with sepsis but negative by standard blood cultures and diagnostic/laboratory testing. Other moms share that their babies appeared healthy at birth and only later on started developing symptoms. Once again, a review of TORCH infections highlights that systemic infection in a baby *may not be obvious at birth* and absence of clinical symptomology in the infant at birth may be misleading if the infant is assumed 'healthy' without longitudinal observation and follow-up.¹ In-utero infection may lead to late-onset disease and may not manifest with signs and symptoms until weeks, months or years later¹. Infants with congenital HIV are often asymptomatic at birth and only 30% of infants are PCR positive at birth.¹ Furthermore the median age of onset for signs of congenital HIV infection is approximately 3 years.¹

In the long-term as these babies grow up into children and teens, many mothers have indicated symptoms in children whom they believe may have been infected in-utero. Obviously not all children have all these symptoms.

<ul style="list-style-type: none">• ADHD• failure to thrive• light/noise/skin sensitivity• chest pain/palpitations• bladder pain, pain with urination• autism spectrum disorder• Tourette's• suicidal tendencies, ideation and attempts• joint and muscle pain• frequent upper respiratory infections• cyclical vomiting syndromes	<ul style="list-style-type: none">• headaches• dark circles under eyes• unexplainable abdominal pain• rashes• atypical seizures, sense of body vibrations• complex pain syndromes• neuropsychiatric symptoms• panic attacks, night terrors, anxiety• cyclical fevers• fatigue• idiopathic or juvenile rheumatoid arthritis
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These symptoms align with the common symptoms in gestationally (congenitally) infected children reported by internationally renowned Lyme pediatrician Dr. Charles Ray Jones. His paper was not included in the SR but we believe his clinical expertise and observation treating over 30,000 children from all over the world warrants careful examination. Dr. Jones presented at an International Lyme and Associated Diseases Society (ILADS) conference in 2011, in Toronto, Canada. His comprehensive presentation here: <https://tinyurl.com/y8b2hdeg>

Considering the well-documented reality that Lyme disease is a protean infection which can cause multi-systemic manifestations, this heterogeneous range of symptoms only makes rational sense.

Many of these children, once Lyme and co-infections have been identified and treated appropriately often including longer-term courses of antibiotics and other immune support, have shown miraculous improvement and renewed health, joy and being able to live out their full potential.

First Nation/Indigenous Health:

We are also very concerned about the potential of in-utero exposure of Lyme and co-infections in First Nations/Indigenous babies and children, as many reserves are located near Lyme endemic areas known to have high-levels of infected ticks. We recently shared these concerns as invited speakers at a townhall on Lyme disease hosted by Six-Nations Health Department and also at a lunch n learn for nurse practitioners who specialize and practice in Aboriginal health. We have also shared our concerns in-person and in-writing with Minister of Indigenous Affairs Jane Philpott as well as the Medical Officer for First Nations and Inuit Health, Department of Indigenous Services Canada.

Lyme and Suicide, Neuropsychiatric Symptoms:

One of the issues we recently highlighted was the huge concern of the high rate of childhood/youth suicides/suicidal ideation identified in Aboriginal/First Nations communities. We have also heard from families all across Canada who have shared that their children with Lyme have struggled with depression, suicidal thoughts, attempts and other neuropsychiatric symptoms.

We realize this is a complex, multi-faceted situation, however we believe these questions should be asked and explored:

1. Could tick-borne disease including Lyme disease have a possible role in this?
2. Could underlying, untreated infection be a possible factor?

In a study published in the Journal of Neuropsychiatry and Clinical Neurosciences (2001), amongst children who were diagnosed with Lyme disease, 40% (8/20) had self-rated they had suicidal thoughts and (2/18) had made a suicide gesture.

<https://neuro.psychiatryonline.org/doi/full/10.1176/jnp.13.4.500>

A recent paper authored by psychiatrist Dr. Robert Bransfield investigating the association between suicide and Lyme and associated diseases, identified a higher rate of suicide in individuals with greater outdoor exposure. Perhaps this could also be extended to individuals including children, youth and adults who live and engage in recreational activities in endemic Lyme areas with exposure to tick-bites and/or in-utero transmission. We believe with information and critical thinking, these important questions must be asked and explored in further depth

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5481283/>

An informational handout on Psychiatric Lyme has been made available by International Lyme and Associated Diseases Society (ILADS) and provides helpful information related to neurological and psychological manifestations of Lyme disease and they highlight that 'Emotional and/or Cognitive disorders can be the only symptoms of Lyme disease'. <https://www.ilads.org/wp-content/uploads/2018/04/brochure-psychiatric-lyme-disease.pdf>

Recent Study Highlights only 3-4% of Canadians officially diagnosed with Lyme:

The significant issues around in-utero transmission can be coupled with a recent publication authored by Dr. Vett Lloyd and Dr. Ralph Hawkins. <https://doi.org/10.3390/healthcare6040125> This study suggests (based on public health data), that 96% of Canadians with Lyme disease are being missed and only 3-4% of Lyme cases are officially diagnosed. As we have already identified, many mothers may be misdiagnosed, undiagnosed or asymptomatic during pregnancy and possibly transmit Lyme disease to their baby in-utero.

Published Research Suggests only 3-4% of Lyme cases are officially diagnosed

Mount A biologist co-authors research that suggests only 3-4% of Lyme cases are officially diagnosed

CBC News - Posted: Oct 20, 2018 7:00 AM AT | Last Updated: 32 minutes ago



Vett Lloyd is a researcher with the Mount Allison University Lyme Research Network. (CBC)

A new study published in the journal Healthcare suggests the vast majority of Canadians who have Lyme disease are slipping through the cracks.

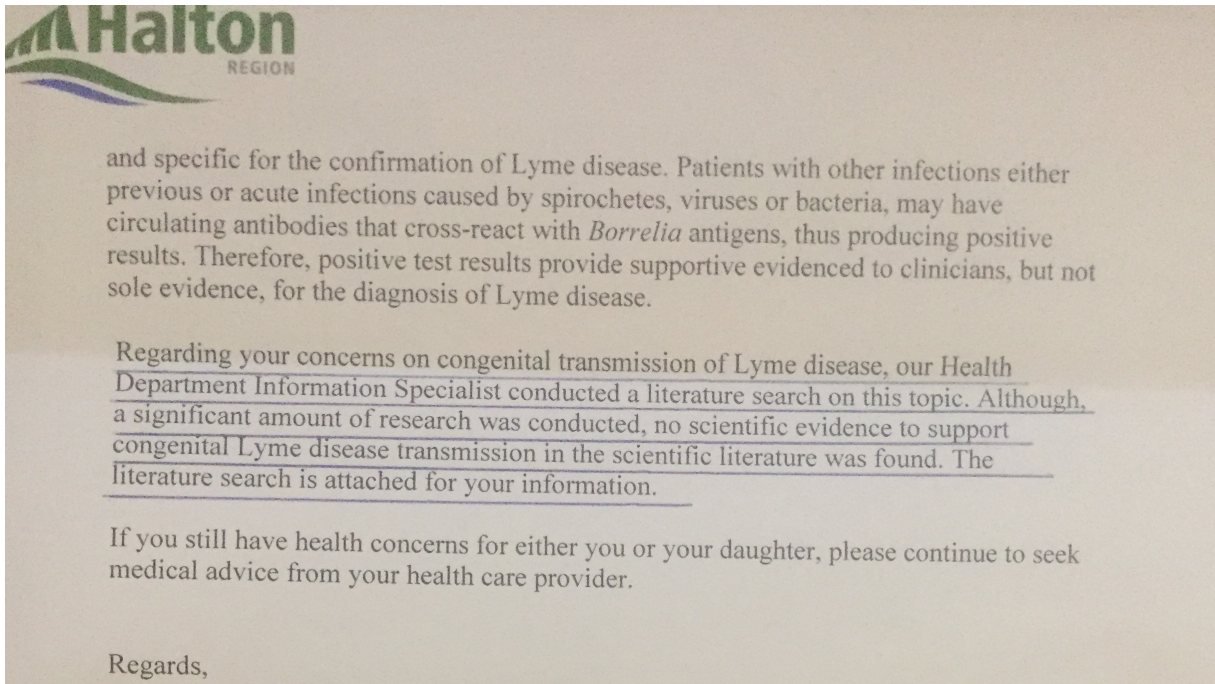
A new study published in on-line journal HealthCare by Canadian clinician and Canadian Researcher indicates that only 3-4% of Lyme cases are officially diagnosed using current testing criteria.

The reality of what we may be dealing with, is indeed sobering and ultimately requires **urgent investigation**, thus once again our request for a **Federal working group specifically to address these issues**. There is valuable data and similar symptom patterns that can be extracted from interviewing and researching affected families and furthermore examining and extrapolating further data – we believe that this would provide much more insight and clarity into helping pave a direction for future research, identification, diagnosis and appropriate treatment for those affected.

We must Reflect on the Past and Identify Misinformation to Correct it:

It is important for us to pause, reflect and take careful note of what is currently accepted/understood in public health circles, academia and amongst front-line professionals as reflected in public comments which have been recently stated through various media outlets or written documentation by high-level Canadian medical authorities, scientist and public health experts.

1: Public Health Ontario: stated in a letter to myself dated January 2017 when I first asked about risk of in-utero transmission: '**No scientific evidence** to support congenital Lyme disease transmission in the scientific literature was found.' The literature search they gave me included two foundational case-reports which documented in-utero transmission.



2: On Mar 10th 2017, Dr. Carolyn Quach past President of AMMI Canada (Association of Medical Microbiology and Infectious Disease, Canada) was interviewed on CBC Ottawa Morning radio. She was responding to an earlier interview where advocates had spoken of alternate modes of transmission. In the transcript of the show, at time

7:52 Radio Host: "Can Lyme disease be transferred in the womb for example?"

Dr. Quach response: "...**there is no evidence** that is actually happening ..in fact, even in animal models, mice that were infected with Lyme disease did not transmit it to their offspring. So, there's no animal models to support it and there **hasn't been any evidence in the humans that has happened at least not reported in literature.** For everything we have peer reviewed journals that review articles from scientists, so as long as that data is not available through the medical literature...**to us there is no proof that it actually happens.**'

3: On March 3rd, 2018, Dr. Tara Moriarty, a scientist from the University of Toronto and initially a Co-Director of the Canadian Lyme Disease Research Network, tweeted out in response to a Twitter post shared by LymeHope. As an aside, the CLyDRN was granted \$4 million to study Lyme disease by the Federal Government.

Dr. Moriarty's response:

*"Did you know that **there is NO evidence** supporting claim that #LymeDisease is transmitted congenitally? It's worth being skeptical of anyone who claims it is, because they may be taking you for a ride. If you have any questions, I'm happy to help sort out facts from fiction."*

Following on from this same Twitter feed, she went further:

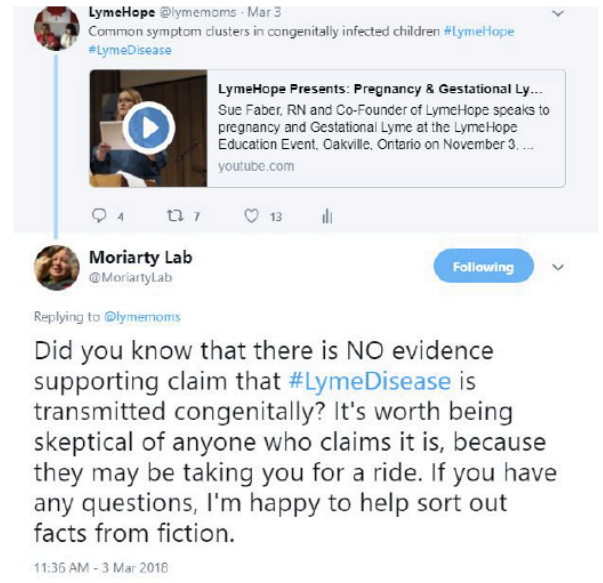
"...any study that has looked at possibility of congenital LD in kids is confounded because kids can pick it up in environment. I'm not saying it isn't possible but you can't say with certainty that it does happen. Anyone who claims this is bullshitting desperate people."

4: Chief Medical Officer for Nova Scotia – Dr. Robert Strang - stated in a full-page article featured in the Chronicle Herald where he was addressing in-utero transmission and stated.. **'There is no evidence** of this.' <https://www.thechronicleherald.ca/opinion/dr-robert-strang-nova-scotias-health-system-has-a-handle-on-lyme-242109/>

In another article (published Sept 7th 2018) in Nova Scotia where a case of in-utero transmission was described, the NS Health department was interviewed and was quoted as saying: **"there is no documented evidence** to date linking maternal Lyme disease and congenital transmission or adverse outcomes of pregnancy." <https://www.thechronicleherald.ca/news/reported-cases-of-lyme-disease-in-nova-scotia-on-rise-239384/>

For medical/scientific/public health experts to make unequivocal statements that 'there is NO evidence' in animal models and 'NO evidence' of in-utero transmission resulting in congenital Lyme and adverse outcomes in humans, is factually incorrect.

Canadian public and healthcare professionals intrinsically trust the word of experts in Public Health and other professional associations and do not typically question their authority on issues of this importance. Indeed, this pervasive message of **'there is no evidence'** continues to result in dismissal, harm and negligence to families, babies and children unable to access appropriate patient-centred care today - for what they believe to be in-utero transmission because they are told, as I was, 'there is no evidence' and that 'it can't happen.' This rigid denial considering the evidence that does exist results in a violation of basic human rights. How many Canadian babies, children and adults have been misdiagnosed and remain untreated and sick as a result?



The *Supreme Court of Canada* has described negligence as "Conduct is *negligent* if it creates an objectively unreasonable risk of harm. To avoid liability, a person must exercise the standard of care that would be expected of an ordinary, reasonable and prudent person in the same circumstances. The measure of what is reasonable depends on the facts of each case, including the likelihood of a known or foreseeable harm, the gravity of that harm, and the burden or cost which would be incurred to prevent the injury."

Clearly PHAC has a *duty of care* to Canadians in the realm of Public Health. As you are well aware, experts are making materially incorrect public statements which contradict the body of evidence which does exist. Severe harm that can result from such ignorance to mothers and babies, is very foreseeable and, it seems to us, is definitely creating an 'objectively unreasonable risk of harm', harm which can include fetal death and disability and furthermore, undiagnosed, untreated infection resulting in suffering.

Physicians, healthcare providers and members of the public rely on PHAC's website and bulletins as an authoritative source for health and *therefore it is incumbent on PHAC to ensure there is a broad education campaign to ensure that the risk of in-utero transmission and risk of adverse outcomes is disseminated and clearly communicated.*

Q: How will PHAC fulfill its mandate to 'promote and protect Canadians' health by preventing and controlling chronic and infectious diseases' and ensure that the clear information about the risk of in-utero transmission of Lyme disease and adverse outcomes (as identified in your SR) is properly communicated to all front-line physicians, nurse-practitioners and sub-specialists?

Looking to the Future and Critical Next Steps:

Now that PHAC authors have acknowledged that in-utero transmission can occur and has been reported as evidenced by peer-reviewed literature as well as risk of adverse outcomes as evidenced by the results of the meta-analysis, we now have a meaningful platform by which we can collectively transform the misinformed narrative of 'no evidence', to high-lighting and acknowledging the truth of the evidence that does exist and utilizing the Precautionary Principle in clearly identifying this alternate mode of transmission and taking urgent measures to engage in research and communicating the risks to Canadians.

In closing, we personally wanted to take the time to thank each of you at PHAC **for identifying and communicating the evidence which does exist on in-utero transmission of Lyme disease** and risk of adverse outcomes – **this is a historical step in the right direction.** This is the very beginning of a critical process and we know that progress takes time – however, we are happy to continue our partnership with PHAC on these critical issues as trusted stake-holders. We trust that our contribution and collaboration with PHAC on the Systematic Review will be publicly acknowledged.

We are so thankful for the ongoing support, concern and commitment to Canadians offered by our elected Federal representatives – MP's and Senators. We have personally met in Ottawa, with over 50 MP's and Senators and shared hard-copies of our Ticking Lyme Petition which now has over 82,500

signatures and over 14,750 personal petition comments. All MP's who read the comments from their constituents are concerned.

This ongoing Canadian Lyme Petition <https://www.change.org/p/minister-petitpas-taylor-ticking-lyme-bomb-in-canada-fix-canada-s-lyme-action-plan-now> continues to highlight the disturbing reality of the escalating Lyme crisis in Canada. This crisis will only continue to grow and snowball. This truly is a non-partisan issue which affects all of us, current and future generations. Silence, apathy, semantics, avoidance and dismissal are not viable options – we need an all-hands-on-deck 'Manhattan Project' approach, anchored in trust, empathy, critical thinking, problem-based learning and collaboration.

We must always put ourselves in the shoes of those who are affected, listen to them and undergird our decisions anchored in transparency, inclusivity, scientific rigor and stake-holder engagement including patient-identified research priorities.

Our extensive compilation of the research and literature on Lyme and Pregnancy and Congenital Lyme Borreliosis can be found here, along with two personal letters from Canadian mothers concerned about their babies. <https://www.lymehope.ca/advocacy-updates/march-03rd-2018>

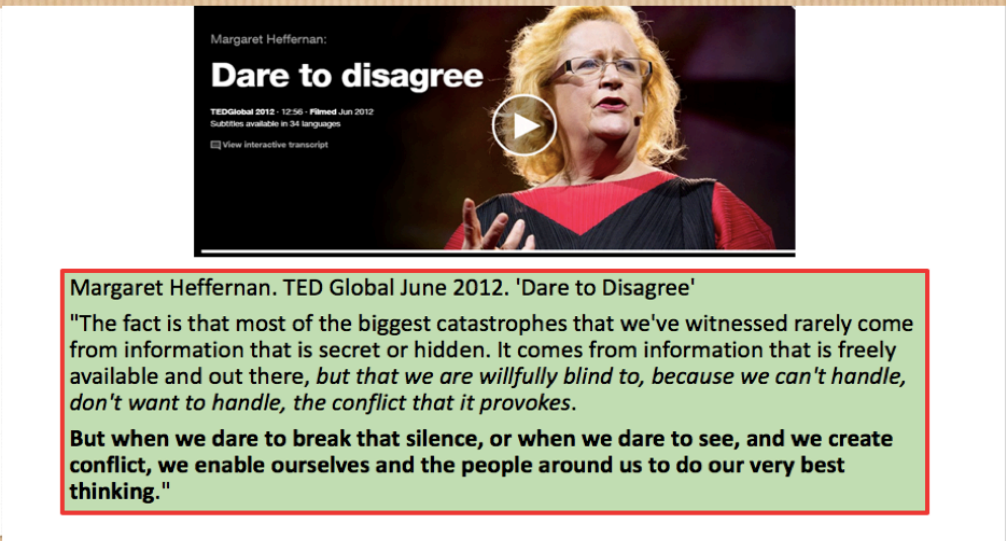
We look forward to your response on our questions and requests including:

- 1:** When will PHAC and Health Canada issue a national press release to highlight the concerning results of your SR - including transplacental transmission and adverse outcomes?
- 2:** How will PHAC authors officially acknowledge our participation, input and review of the draft which resulted in revision and changes?
- 3:** When will PHAC update your website on 'Lyme and Pregnancy' and 'Causes of Lyme Disease' to include transplacental/in-utero transmission and adverse outcomes?
- 4:** How will frontline medical professionals and all Canadians be alerted to these updates and alerted to this alternate mode of transmission as well as risk of adverse outcomes?
- 5:** When will LymeHope's meeting requests with Dr. Tam and Honorable Minister of Health Ginette Petitpas-Taylor be granted?
- 6:** Will Canadians who wrote the Lyme Letters received by PHAC be acknowledged and receive a personal response?
- 7:** How will PHAC fulfill its mandate to 'promote and protect Canadians' health by preventing and controlling chronic and infectious diseases' and ensure that the clear information about the risk of in-utero transmission of Lyme disease and adverse outcomes (as identified in your SR) is properly communicated to the public and indeed all front-line physicians, nurse-practitioners and sub-specialists?

8: When will PHAC initiate a Federal Multi-disciplinary working group with LymeHope as an active partner to specifically focus on in-utero transmission and congenital Lyme borreliosis and tackling the significant public health implications to this alternate mode of transmission?

We must move forward with meaningful momentum on this issue. At LymeHope, we count it a privilege to speak out and advocate on behalf of those who feel they have no voice. It is time that ALL voices are heard, validated and acted upon. We must work together.

In closing we share the compelling words of Margaret Heffernan as spoken in her TED Global June 2012 talk - 'Dare to Disagree'. We believe Canada can be a global leader and we trust that the time has come for all of us to come together and engage in our 'very best thinking' - for the sake of our fellow Canadians and future generations.



Margaret Heffernan:
Dare to disagree
TEDGlobal 2012 - 12:56 - Filmed Jun 2012
Subtitles available in 34 languages
[View interactive transcript](#)

Margaret Heffernan. TED Global June 2012. 'Dare to Disagree'
"The fact is that most of the biggest catastrophes that we've witnessed rarely come from information that is secret or hidden. It comes from information that is freely available and out there, *but that we are willfully blind to, because we can't handle, don't want to handle, the conflict that it provokes.*
But when we dare to break that silence, or when we dare to see, and we create conflict, we enable ourselves and the people around us to do our very best thinking."

Warmly and with Hope,

Sue Faber RN, BSc(N)
Jennifer Kravis BA, LL.B
Tamara House
LymeHope
www.lymehope.ca

***'If the mind doesn't know, the eyes don't see.'* - Dr. Charles Ray Jones, ILADS, 2018.**