

**Jennifer Diana Kravis – Brief**  
**House of Commons Standing Committee of Health**  
**Study into the Federal Lyme Framework, June 6, 2017**

**Biography:**

46 year old married mother of 2 living in Oakville, Ontario. B.A. in Political Science from Western University; LL.B from University of British Columbia and a graduate in the top 10 of my class. Practiced corporate securities law at Davies Ward Phillips & Vineberg for 4 years earning the title of Junior Partner; then was an Executive at TD Bank in the field of Executive Compensation for 7 years until at age 36, 11 years ago, I was suddenly totally debilitated by a “mystery virus” that no doctor could identify. I became bedridden, sidelined, disabled, abandoned, financially stressed and a single mother when my marriage fell apart. After 5 years, I received a positive blood test and a clinical diagnosis in the US of Chronic Lyme, Bartonella and Babesia. I paid for 2 years of antibiotic treatment in the US with a very compassionate and experienced Lyme Literate Medical Doctor which has significantly improved my quality of life, and thereby my whole family’s quality of life. In 2013 I learned both my children had Chronic Lyme, possibly passed by me to them in pregnancy. In 2016 I met Sue Faber on Facebook and together we started LymeHope and advocating on behalf of Canadian families.

**Appendices:**

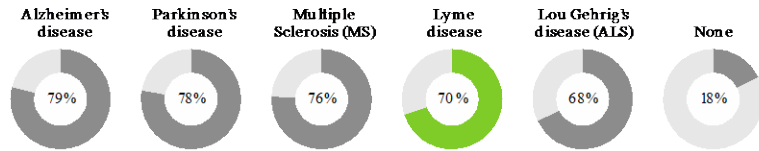
1. March 2017 Canadian Benchmark Survey on Lyme Disease
2. LymeHope’s Hope for Canada
3. Researcher John Scott’s Letter to Minister Philpott
4. My “Lyme Letter” to Minister Philpott – one of the thousands still undelivered & unread by her

# Appendix 1

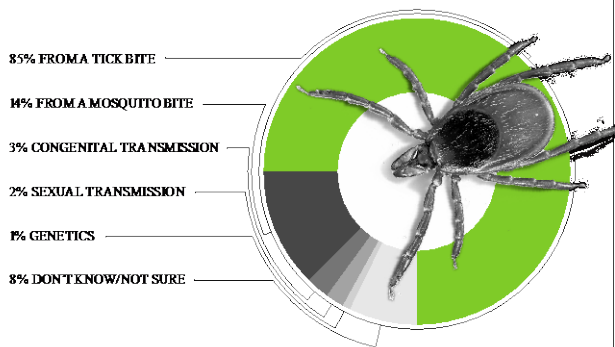
## Lyme Disease in Canada A benchmark public opinion study, 2017

Canadians know Lyme disease by name. Most acknowledge having some information about the disease, such as it being contractible via a tick bite

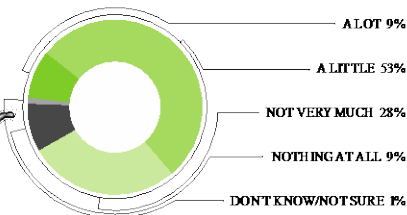
Which of the following diseases have you heard of?



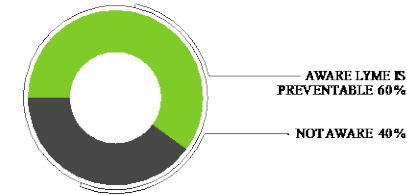
To your knowledge, how can a person contract Lyme disease?



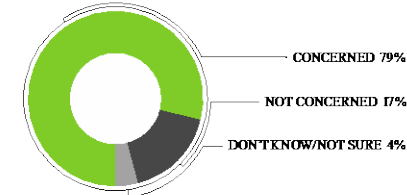
How much would you say you know about Lyme disease?



A full 40% of Canadians are NOT aware that Lyme disease is a fully preventable disease



Almost 80% of Canadians are generally concerned about getting Lyme disease



One in ten Canadians claim that they or someone they know in Canada, has been diagnosed with Lyme disease. Compared to the number of reported cases by the Public Health Agency of Canada for 2015, this exposes a potentially HUGE gap (917 reported cases vs. ~3 million people claiming to have been diagnosed) in the prevalence of this disease (even within the margin of error of 3 percentage points at the 95% confidence level)

Disease/Disorder	# of cases in Canada (as of 2015)*
Fibromyalgia	1,000,000
Chronic Fatigue Syndrome	1,000,000
Alzheimer's/other dementias	747,000
Parkinson's	100,000
MS	100,000
ALS/Lou Gehrig's disease	3,000
Lyme disease	917

Have you, or someone you know in Canada, been diagnosed with Lyme disease?



- Online study with Canadians aged 18+
- English and French language
- Margin of error +/- 3 percentage points, 19 times out of 20, had the entire population of Canada been surveyed
- Nationally representative sample by region, gender, age, work status, children at home status
- Data collected between March 7 and 12, 2017
- N=1,200 in interviews



PERFORMED DESIGN, ANALYSIS AND REPORTING  
Angela Muzzo, MBA, Founder  
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COMMISSIONED TO CONDUCT DATA COLLECTION AND PROCESSING

## Appendix 2

## LymeHope's Hope for Canada

1. That Canada would be a world leader and be the catalyst that will result in other Countries following, steps that would literally save the lives and futures of millions and millions of people around the world.
2. That there will be a full and fair investigation into our Public Health, the Association of Medical Microbiology and Infectious Disease, the Queen's Research Hub, and the relationships, ties and conversations between the Centres for Disease Control and the Infectious Disease Society of America, to assess and determine conflicts of interest, what has been known and not disclosed regarding this disease, and who is responsible for perpetuating the lies and the suppression of this disease and unspeakable suffering and abuse against hundreds of thousands of Canadians.
3. That the National Microbiology Lab (Cadham Lab) where all Lyme testing is done, will disclose full banding patterns on Western Blot tests (including bands 31 and 34) to the doctors and patients, and to release all previous archived banding patterns.
4. We would get legislation that would protect doctors who do choose to treat from harassment, investigation and/or discipline, and that would require labs to provide disclosure of Lyme test limitations like many US states have done.
5. For a research budget for Lyme that is in line with other major diseases and proportionate to the severity and prevalence of this disease, and that research would be granted to ethical, unbiased, transparent, patient-centred priorities.
6. That there could be a public awareness campaign which educates Canadians about the prevalence, risk, signs & symptoms, limitations of testing, how to safely remove a tick and the urgency of immediate treatment, NOT just about prevention and pulling socks up.
7. That all medical professionals were trained on how to clinically diagnose and treat patients with multiple acute AND late stage, disseminated, chronic Lyme & Co-infections.
8. One day, an apology to doctors who have been harassed, sanctioned and/or stripped of their licence, and to the hundreds of thousands of Canadians who have suffered devastating effects of undiagnosed or misdiagnosed Lyme & Co-Infections.
9. That Lyme patients could once again trust and depend on their doctors to be educated about their disease, listen and believe their patients suffering, that they would treat and care for patients with kindness, compassion and respect.
10. That no one else gets Chronic Lyme

## Appendix 3

365 St. David St. South, Fergus, ON N1M 2L7

The Honourable Jane Philpott  
Health Minister  
Health Canada  
Confederation Building, Suite 162  
House of Commons  
Ottawa, ON K1A 0A6

2 June 2017 (sent via email)

Dear Honourable Minister:

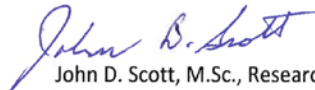
I have to chuckle when I hear your lips and vocal cords tell me there is a direct correlation between tick numbers and climate change. This pronouncement recently occurred when you addressed the press regarding your presentation on *Lyme disease in Canada—a Federal Framework*.

In summer, blacklegged ticks, *Ixodes scapularis*, go down into the cool, moist leaf litter and re-hydrate. In winter, they descend into the leaf litter and upper topsoil, and are comfortable under an insulating blanket of snow. They have antifreeze-like compounds (glycoproteins) in their bodies and withstand sub-zero ambient temperatures. Blacklegged ticks are eco-adaptive.

At Kenora, Ontario, ambient temperatures dip to  $-44$  degree Celsius and, in summer, reach 36 degrees Celsius. Blacklegged ticks handle these extremes in temperature year after year. Based on other *I. scapularis* findings in Ontario (i.e., Long Point, ON on the north shore of Lake Erie) and the infection prevalence of *Borrelia burgdorferi* in Corkscrew Island population, I estimate that this tick species has been established on Corkscrew Island, Ontario (near Kenora, ON) for more than 50 years. Notably, the *I. scapularis* adults have an infection prevalence of 73% for *Borrelia burgdorferi* on Corkscrew Island (Scott et al. 2016)—the highest ever recorded in Canada.

Why is the federal government spending research dollars on ticks and climate change? As a taxpayer and, as a tick and Lyme disease researcher, spending millions of dollars on ticks and climate change makes absolutely no sense whatsoever.

Sincerely,

  
John D. Scott, M.Sc., Research Scientist

## Appendix 4

March 20, 2017

Dr. Minister Philpott:

This is my Lyme Letter. My Lyme story. Like all the others, it is sad, and all too familiar to those in the crazy world of Lyme disease. My daughter, now 12, also has chronic Lyme, Rocky Mountain Spotted Fever and Bartonella (the latter two diseases confirmed by Canadian tests). My other daughter 14 also has chronic Lyme and multiple co-infections, encephalitis causing neuro-psych issues and is developing arthritis in the spine.

My mother also had a tick bite and bullseye rash almost 10 years ago. Finally, my dog got a tick bite and contracted Ehrlichia. Of the 4 of us, **only my dog got compassionate and prompt care**, he received 5 x 30 day doses of antibiotics and he has made a full recovery. My daughters, my mother and I did not, and we all suffer every day from chronic symptoms. I have been fired by 4 doctors in 6 years since my Lyme diagnosis, my daughter has just been fired by her family doctor.

My niece at age 12 developed a bullseye rash in Oakville Ontario a couple years ago. I had to help my sister fight – she had to see 4 different doctors before ONE would agree the bullseye rash was Lyme Disease and give treatment. The first said it was a spider bite, the second said it was lupus and the third stated there was no Lyme in Ontario.

It's been 11 years since I first developed double vision out of the blue at age 36, followed by a myriad of strange neurological symptoms that led a multitude of doctors to throw around scary diagnoses like a brain tumour, cancer, MS, Guillan Barre syndrome, hypothyroidism, bipolar, depression, anxiety, atypical autoimmune disorder, malaria and an eventual throwing of the hands and declaring me "healthy" but an unfortunate victim of chronic fatigue syndrome and fibromyalgia triggered by a "mysterious virus or bacteria of unknown origin".

I sat in a top neurologists office listening to him tell me "good news you are totally fine" while I tried to explain I had crushing cyclical headaches, numbness, tingling and burning pain from the tip of my nose to the bottom of my toes (that lasted almost a year and still persists in my extremities to this day).

For 12 months I continued pushing through my executive job in Toronto every day, while making the rounds of specialists and appointments, living in a semi-state of terror and stress with various body systems falling apart and doctors all scratching their heads over my "mystery illness". I had MRIs, CT scans, x-rays, sleep studies, evoked potential tests, neurological exams and hundreds of blood tests. My 40 page OHIP summary details appointment after appointment, with infectious disease, internal medicine specialists, 3 neurologists, a respirologist, an ophthalmologist, an endocrinologist, a rheumatologist, and more.

Eventually, within the year the collapse was complete, and I was sent home with painkillers, sleeping pills and anti-depressants (for the inevitable depression I was told I would eventually fall into) and told that I had chronic fatigue syndrome and fibromyalgia, that they are incurable

and there is no treatment. I packed up my office and told my co-workers I would be back in 3 months. That was 11 years ago and I have not worked since.

After my first attempt to return to work and the subsequent relapse, I became a prisoner in my bed, unable to get up except to limp my way to the kitchen to find food and to go to the bathroom. I watched the seasons change and weeks and months pass from my room, unable to read, watch TV or talk on the phone. I was an uncommunicative prisoner in my own body.

For almost 1 year I only saw my children, then 2 and 4, when they came into my room and sat on my bed to visit and watch cartoons – me awake but unable to actually keep my eyes open due to the crippling and profound fatigue that is difficult to explain. It was a nightmare that gripped me with unimaginable despair and fear for my future. I languished in bed while my little girls were raised by a full time nanny and their father. I am so thankful we were able to afford this help because so many sick Canadian moms cannot.

For the next three years, I was unable to go to a mall, grocery shop or drive long distances. I developed a fear of going out, as frequent and unpredictable “attacks” would render me incapable of walking and required me to lie down with no notice.

I had to say “no” to my little girls every day. “No I can’t play with you”, “no I can’t bathe you”, “no I can’t climb upstairs and tuck you in today”, “no I can’t go watch your soccer game”, “no I can’t push you on the swing – I can’t even walk from the couch to a chair outside to watch you”, “no I can’t take you to Wonderland”, “no you can’t have friends over it will be too noisy”, “no I can’t volunteer in your class”, “no I can’t take you to the movies”, “no I can’t play cards or dolls”. I listened to my little girls cry daily because I couldn’t play with them, pick them up or give them a bath and tuck them into bed.

I literally missed years of their lives, precious time and experiences I can never get back. That was more heartbreaking and worse than any aspect of the illness.

I went from working full time in an executive job in Toronto, exercising 3-4 x per week and being “that woman that seemed to do everything” to being unable to walk 5 minutes to the end of the driveway. For almost 4 years, I had to lie down in my bed for at least 3-4 hours almost every day just to get through the day. Progress was glacially slow and measured in 6 month to 1 year intervals with huge swings of bad to “ok” in between.

Life continued, I learned to adapt my expectations and my routines. In 2009, 39 years old, I went to Disney Land with my children and spent the week riding an electric scooter as I was unable to walk through the parks. Being out for the whole day resulted in a punishing cycle leaving me sobbing and shaking in bed every afternoon on this trip, and for weeks after, but as a parent you are willing to give up a lot to make your kids dreams come true. Still, my desire to return to my job led me to request a second attempt to return to work. Denial is powerful; this resulted again in an almost instant relapse that took months to recover from.

A disease that could have and should have been immediately diagnosed and cured with mere weeks of antibiotics has turned into a lifelong chronic illness that affects me and my family every day, ended my promising career, ended my first marriage, and has changed my life forever.

For 11 years I have endured constantly changing symptoms affecting so many organs and systems - daily, often crippling pain, panic attacks, bouts of depression, severe insomnia, debilitating and constant fatigue, explosive migraines, rashes, burning, stabbing neuropathic pain, stuttering, short term memory deficits that leave me being unable to recognize people I met recently and talked to for a half hour and cause me to miss things like appointments, birthdays and graduations on a regular basis, seizures, pain in the soles of my feet, painful trigger points requiring painful, monthly injections, vision changes, hair loss, twitching, spasms, early menopause, drenching night sweats and lethargy so bad I sometimes cannot recognize myself.

Some days I can function quite normally out doing multiple errands and going out for dinner. Other days (often entirely unpredictable) I spend entire days in my pyjamas, wandering in a fog from bed to couch, unable to even think about cooking dinner or going out to get the mail, while I lie on the couch in a fog of despair and depression.

I have been officially and unwillingly forced out of my former role as perfectionist and overachiever. Lyme is insidious; it literally sucks the life right out of me and I spend much of my life feeling like time is passing by and that I'm not fully living. It affects my family and their lives and happiness every day.

No one has worked harder or been more dedicated to restoring my health and return to work than I have. It has been my single focus since the day my Dr forced me onto sick leave over my protests. I have been to almost 500 appointments with alternate healers. I have spent \$286,746 trying every possible treatment I could find: osteopathy, chiropractic, naturopathy, homeopathy, nutritional IVs, injections, bio-identical hormones, psychotherapy, hypnotherapy, physiotherapy, acupuncture, bee venom stings, allergy testing and treatments, bio-resonance machines, infrared sauna, hyperbaric oxygen tanks, heavy metal removal, laser treatments, chinese herbs, reflexology, reiki, Rife machines, neuro-linguistic programming, detox diets, meditation, energy healing, personal training and hundreds of lab tests such that my left arm veins are permanently damaged. I have consumed over \$50,000 of prescription drugs, trying 60 different drugs to get better, enduring all the side effects on top of my illness. At the same time, I estimate my lost wages to be over \$3 million. Collecting disability has not exactly been a windfall. These are extreme lengths to go to for a person that "has nothing wrong with them".

Pacing and planning my days and weeks was a full time job. If I went out dinner, I knew not to make any plans for the day before, the day of or the next morning. I have learned to accept that bills pile up, I forget about them and they go unpaid. A perfect credit score no more. I crash pretty much every single time I travel with my family; I have been to emergency rooms in different countries.

I live with a chronic energy deficit – every decision whether it’s walking the dog, showering, cooking a meal, or trying to get bills paid – requires me to analyze how much energy I have that day, how much energy the activity in question will require, and whether it will result in a crash that might debilitate me for days after. Sometimes I make choices to engage in activities I know will cause me to crash and suffer afterwards, because it makes me feel alive and helps me remember what life used to be like.

The brain fog is one of the scariest symptoms. My mind was my livelihood and so much of my personality. I am a member of MENSA, scored in the top 2 percentile on my LSAT, graduated at the top of my Law School class, and enjoyed consistently excellent work performance ratings. Just before I had to leave work, I was promoted to Vice President at my Bank and given a rating of “exceptional”, the highest possible rating. I was identified as “high potential” in the Bank, and was being coached and groomed as a candidate for an an SVP job that would have doubled my income.

I forget conversations, people I’ve met, what happened in a show I watched a week ago. I find myself in a room knowing I went to get something but unable to remember what it was. A few years ago, I got up and got dressed for my godson’s graduation, and then forgot about it so was sitting in my kitchen while he received his diploma. I couldn’t read books anymore, which was one of my favourite pastimes, as I can often not recall or retain what I’ve read. During conversations I blank out and realize I just missed part of the conversation. I developed a stutter and slurred speech sometimes when stressed or tired such that sometimes I appeared drunk.

My body now controls my life. There’s no such thing as “pushing through” or “catching up”. I sometimes need frequent breaks and rest, just to get through the day. I suffer continual guilt about the impact and burden this creates for my family. My husband gets my girls up every morning and feeds them breakfast, as everyone knows if I have to get up before 9 or 10am it will be a long and bad day for me. They eat more take out than they should because many nights I’m completely exhausted by 4pm and need to sit or lie down for the rest of the night. I live in a chronic state of anxiety, trying to get done all the things I have to do in my life, never knowing whether tomorrow will be a good day or a bad one.

My husband works hard all day to support all of us, and then he has to come home and tidy up and cook and clean because I used all my energy up on something else I had to do that day. My beautiful golden retrievers never complain when I don’t make it out for their walk but their sad eyes break my heart and stoke my guilt. I’m still the Type A, hard working, overachieving perfectionist in my heart and mind, but my body rejected that way of living a long time ago.

No one can tell me what will happen in the future. Will I get better? Lyme is a complex condition... will I develop MS, ALS, cardiac disease, dementia, lose my ability to walk and be in a wheelchair like so many others do with chronic Lyme disease? No one can say for sure.

It took 5 years for me to obtain a diagnosis that should have been instantly recognized...LYME DISEASE. This diagnosis came from a US physician and was confirmed with a positive Western



Blot after a provocation challenge with a few weeks of antibiotics. I've been tested for Lyme in Canada several times but the Elisa remains negative, and as you know, no amount of begging or money will grant me the right to have a western blot here. I have since tested positive with Bartonella in Canada. Which my GP thought was Bordatella (Kennel cough).

My absolute elation at having my prayers for an explanation and diagnosis (and cure I thought) was quickly shattered once I understood the shameful and shocking reality for Lyme sufferers in Canada – NO recognition, NO empathy, NO treatment. Just marginalization, disdain, and disbelief. And after 5 years of unbridled bacterial dissemination into my brain, bones, joints, tissues, eyes, muscles and organs. NO CURE.

Like most have experienced, my referral to an infectious disease specialist was a horrible experience. This doctor, upon realizing the word "Lyme" on my file, actually ordered me to leave her office within the first 2 minutes. I left in tears, asking her "why are you refusing to talk to me? Isn't Lyme supposed to be a clinical diagnosis? Why have you not asked me a single question about my symptoms or history?".

I didn't file a complaint about this doctor, nor did I complain when our GP "fired" my daughter after her tests for co-infections came back positive. I didn't file a complaint when the same GP accused me of "creating a hypochondriac" in my daughter when I asked for testing (which by the way, came back positive for Rocky Mountain Spotted fever and Bartonella). Or when she accused my daughter and I of self inflicting a rash on my daughter's arm. Why? Because the experience of others is a clear warning: if you complain about a doctor's treatment around the issue of Lyme Disease, you get "blacklisted" among the medical profession and doctors then will refuse to take you on as a patient. I was also afraid this GP would write in my file that I had Munchausens disease as other Lyme moms have experienced.

Like the other thousands of Canadians suffering from the chronic form of Lyme Disease, I had to travel to the US for expensive treatments. I bombarded my body for 2 years with antibiotics and had a permanent picc line in my arm (which I paid US\$4,500 to have installed in Buffalo), to administer intravenous antibiotics for a year. When I had to visit ER departments at home, I lived in fear that the hospital would pull my picc line out. I had to pay for private nursing care to help me care for this picc line and my husband had the privilege of becoming my nurse.

The two years of treatment were in some ways, harder than the illness. The herxheimer reactions were scary, debilitating and severe. Like so many others, I began to dread going to the ER or to the doctors, as once the word Lyme enters your dialogue, the abuse, ridicule, anger, dismissal, eye rolling and ignorance begins, further traumatizing you when you are in a weakened, vulnerable and frightened state. People with chronic Lyme disease are marginalized, abandoned, ignored, lectured, yelled at, belittled, neglected and dismissed. It is so shocking and hard to believe this happens in Canada, that most people simply cannot believe the unbelievable. But there are hundreds of thousands of Canadians that live this reality and have lived this reality for DECADES.

After 8 years of trying everything under the moon at great personal cost, the antibiotics were transformative. Within days of installing the picc line, a papular diffuse rash I had for over 8 months that no doctor could figure out, completely and permanently disappeared. My brain fog lifted. I could read again, and remember people I had met earlier. I felt like I was waking up after being in a permanent state of fog and confusion. I didn't have to nap every day. I had more energy and more functionality. My quality of life has been dramatically improved, although I am left with chronic fatigue and severe pain.

After almost 10 years of supporting my claim, my insurance company used my "cure of Lyme disease" as a reason to cut off my disability benefits. I had to start a lawsuit, and for a year, deal with surveillance vans videotaping me as I went grocery shopping. Against my lawyer's advice I ultimately settled for much less than I should have received, because I couldn't cope with the stress. Now I cannot work, and I have no disability income except for \$17,000 of CPP Disability. The same insurance company who declared me cured and refused to pay disability, also now considers me "uninsurable" for life insurance.

Lyme is a "DIY" disease, and now I am fighting all over again for my 12 and 14 year old daughters who have both been diagnosed with Lyme and multiple Co-Infections, one with encephalitis (brain inflammation). It cost me \$15,000 to get these assessments, testing and diagnoses. And that is just the beginning. They will both need many years of continuous antibiotic treatment. But at least after seeing this doctor, my daughter didn't cry and ask why no one believes her. They are both likely congenital cases. My children are sick, we have no support, and I as a mother have to be their nurse, researcher, doctor, caretaker, tutor to keep up in school and advocate – a job for which I am ill equipped. We need medical support. HERE. And the ultimate insult is that now border guards are seizing and destroying personal prescription drugs based on a "new directive" from Health Canada. What are we to do now?

My mother, fit and healthy, now sometimes needs a cane due to what looks to be classic Lyme arthritis. When I attended a meeting with her GP and told her about the tick bite, the bullseye rash, and the years of arthritis, the GP's response was to refuse a trial of 3-4 weeks of doxycycline on the basis that they are "dangerous and cause c-difficile", and suggest my mother continue to take steroids and opiates (I guess in her opinion, those drugs aren't dangerous). She also dismissed the possibility of Lyme and suggested it could be gout.

Minister Philpott – Canadians of all ages are being abused, ignored and abandoned. Their lives are being ruined by a disease that is PREVENTABLE and TREATABLE. The status quo is completely unacceptable. How many more people will have to experience this? Please, use your power for good. We need you to stand up for Canadians and do the right thing. Thank you

Jennifer Kravis