Sue Faber – Brief
House of Commons Standing Committee of Health
Study into the Federal Lyme Framework, June 6, 2017

Biography:

39 year old married mother of 3 living in Burlington, Ontario. BScN degree with nursing experience in ER and community case management (CCAC). Diagnosed in Canada with chronic Lyme and positive by Canada's two tier serology after 15 years seeking answers for multiple medical issues including profound fatigue, choking, migratory pain, chronic cough and shortness of breath, palpitations and transient tachycardia, memory issues, neurological symptoms to name a few. I believe my children may have contracted this illness through pregnancy as they have all been sick since birth. My experience with Lyme has compelled me to step into an advocacy role with the combined perspective of RN and patient.

Jennifer Kravis and I are co-authors of the Ticking Lyme Bomb Petition on change.org: http://bit.ly/2lfBuNL and the Lyme Letters Campaign outlined on www.lymehope.ca.

Recommendations and Request for Meetings:

Jennifer and I still look forward to the **opportunity for a meeting with Federal Minister of Health Jane Philpott** so we can deliver on our promise to the thousands of Canadians – men, women and children who have shared their heartbreaking stories, their letters of support of loved ones and sent them to us with the understanding they would be hand delivered by us to the Minister. To date we have collected over 2500 letters. It is my understanding that several MP's and Senators have called or written Minister Philpott's office, in one case hand-delivering a letter - requesting that she meet with us and I also have reached out to her office staff several times over the past several months with the same request for a face to face meeting. Jennifer and I made the trip twice to Ottawa in April and May 2017 with Hopes of meeting specifically with Minister Philpott. Attached is a letter of support written on our behalf by Conservative MP Kevin Waugh.

Jennifer and I also look forward to the **opportunity to meet with Dr. Theresa Tam**, Interim Chief Public Health Officer at Public Health Agency of Canada to further discuss our concerns of congenital/transplacental transmission and collaboratively review and discuss the available body of science and literature with her so as to move forward in a collaborative, open partnership with PHAC including inclusion of congenital transmission as one of the research priorities and the **inclusion of the patient/advocate** voice, expertise, strategies and ideas.

We also look forward to engaging in dialogue and collaboration specifically with regards to congenital transmission with the **Canadian Pediatric Society, Neonatal-Perinatal Medicine**

Section of CPS, Society of Obstetricians and Gynaecologists of **Canada (SOGC), the Canadian Association of Midwives**. We appreciate that after our meeting with Dr. Howard Njoo – Deputy Chief Public Health Officer at PHAC - he agreed to reach out to these groups to introduce Jennifer and myself as patient advocates and facilitate the arrangement of these meetings. We would respectfully request that the **College of Family Physicians of Canada** also be added to this list as frontline practitioners.

It was Health and Welfare Canada which wrote 29 years ago in an 1988 document – attached to this brief – that '**transplacental transmission has been documented.'** It is my understanding that since this time, this alternate mode of transmission has not been studied in Canada and most frontline practitioners are unaware of this potential and very serious risk. I believe this needs to be a high priority area of research, study and education.

– **exerpts from my speech as I spoke as a witness at the Standing Health Committee review of the Federal Lyme Framework.**

'I am calling on each of you here today to lace up your sturdiest pair of well-worn hiking boots and join me as I take the lead for just a few minutes as your guide. What qualifies me to speak to you today isn't a PhD or a position of authority and power, rather, my qualifications come from a personal journey into the hazy, often suffocating shadows of what I like to call the Lymelands where those affected by the same plight must band and unite together to survive.

We the weary, the wounded and the sick, we find each other as we have no choice but to look for answers together. We share an illness which is insidious, disabling, and destructive. A disease which comes like a thief in the night to snatch away childhoods and steal careers. A disease which cripples active contributory Canadians, bankrupts families and breaks down marriages. A disease which in some cases has driven Canadians to end their own lives because they live with excruciating, unrelenting pain which confines them to their rooms and robs them of all dignity, respect and hope. I ask you to take the time and read the three Lyme letters which I have been given permission to share in my brief – to give you a clear and disturbing picture of the reality of suffering of Canadian adults and children alike.

…Thank you for joining me on this uphill climb, we are still far from the top. We know that we must climb to the top because at the pinnacle of this mountain we will experience a freedom and be able to clearly see the truth, a truth which has been veiled and shrouded by controversy for so many years.

Climbing to the top can only be accomplished by reliance and trust of those who have climbed this mountain – **the patients**. They and only they can speak to their journey with clarity and insight. It is devastating that this strong and authoritative voice was completely left out of the Federal Lyme Framework. In fact, the voices, testimonies and pleas of thousands upon thousands of Canadians was clearly blacked out, shut out and in essence ignored.

Despite this failed Framework, I still have great **HOPE** that this isn't the end of the story, but rather the start of a fresh beginning, a re-awakening to the reality of the Lyme crisis which continues to sweep across our Nation. Your decisions and actions on this issue will directly impact the fate of millions of Canadians.'

Please note: This brief exceeds 10 pages as I have included three personal stories which are long, but speak directly to the shocking devastation inflicted upon Lyme sufferers, as well as their families.

Appendices:

1: Health Canada Weekly Diseases Bulletin 1988 – reporting transplacental transmission of Lyme.

2: Letter of Support sent to Minister Philpott by MP Kevin Waugh

3: "Lyme Letters" addressed to Minister Philpott, still undelivered & unread – from a patient, a spouse of a patient and the mother of a young patient

Canada Diseases Weekly Report

Rapport hebdomadaire des maladies au Canada

ISSN 0382-232X

Date of publication: June 4, 1988
Date de publication: 4 juin 1988

Vol. 14-22

CONTAINED IN THIS ISSUE:

CONTENU DU PRÉSENT NUMÉRO:

LYME DISEASE IN CANADA

Lyme disease was first described clinically in 1975 in Lyme, Connecticut[1]. The disease, caused by the spirochete **Borrelia burgdorferi** first identified in 1982, is usually transmitted to humans by infected ticks, although biting flies and mosquitoes in endemic areas have been implicated in transmission[2]. However, the most important vector is the deer tick, **Ixodes dammini**. Ticks also infect numerous types of domestic and other wild animals, resulting in wide geographical spread of the microorganism and worldwide distribution of the disease. In Canada, several species of ticks capable of transmitting **B. burgdorferi** have been identified, and in several instances, ticks have been found to be infected with this organism (Table 1). The first cases of the disease in domestic animals in Canada were diagnosed in 2 horses in south-eastern British Columbia just after the 1987 spring tick season[8].

LA MALADIE DE LYME AU CANADA

La maladie de Lyme, dont la description clinique initiale a été faite en 1975 à Lyme (Connecticut)[1], est due au spirochète **Borrelia burgdorferi** identifié pour la première fois en 1982. Sa transmission à l'homme est généralement attribuable à des tiques infectées, même si des mouches et des moustiques hématophages ont été incriminés dans des régions d'endémie[2]. Le vecteur le plus important est toutefois la tique du chevreuil, **Ixodes dammini**. Les tiques infectent aussi de nombreuses espèces d'animaux domestiques et d'autres animaux sauvages, d'où la vaste diffusion géographique du microorganisme et la répartition mondiale de la maladie. Au Canada, un certain nombre d'espèces de tiques susceptibles de transmettre **B. burgdorferi** ont été identifiées et, dans plusieurs cas, la positivité à l'égard du microorganisme a été observé (Tableau 1). Les premiers cas canadiens chez des animaux domestiques - en l'occurrence 2 chevaux - ont été diagnostiqués en 1987 dans le sud-est de la Colombie-Britannique, juste après la saison printannière des tiques[8].

Table 1. Distribution of Ticks in Canada Known to be Capable of Transmitting B. burgdorferi/
Tableau 1. Répartition au Canada des tiques connues pour être susceptibles de transmettre B. burgdorferi

Tick/ Tique	Animal Host/ Animal hôte	Location/ Endroit	Ticks with Documented B. burgdorferi Infection/ Tiques avec infection à B. burgdorferi documentée
Ixodes dammini - size* varies from 0.5 to 2.7mm[6]/ Ixodes dammini - taille* variant de 0,5 à 2,7mm[6]	Mice, deer/ Souris, chevreuil	Long Point, Lake Erie, Ont.[3]/ Long Point, Lac Erié, Ont.[3]	Yes/Oui
	N.K.**/ Inconnu	P.E.I. (S. McNair, Charlottetown, Dr. P. MacKean, Summerside, P.E.I.; Dr. E.F. Lindquist, Ottawa, Ont.; p.c.***, 1988 /I.-P.-É.(S. McNair, Charlottetown, Dr P. MacKean, Summerside, I.-P.-É.; Dr E.F. Lindquist, Ottawa, Ont.; c.p.***, 1988)	N.K./Inconnu
Dermacentor variabilis - size varies from 0.6 to 5.2mm[7]/ Dermacentor variabilis - taille variant de 0,6 à 5,2mm[7]	Many wild and domestic animals/ Nombre d'animaux sauvages et domestiques	Southern Ontario[3,4]/ Sud de l'Ontario[3,4]	Yes - Long Point[3]/ Oui - Long Point[3]
	"	Southern Manitoba[4]/ Sud du Man.[4]	N.K./ Inconnu
	"	South-eastern Saskatchewan[4]/ Sud-est de la Sask.[4]	N.K./ Inconnu
	"	South-western N.S.[4,5]/ Sud-ouest de la N.-É.[4,5]	N.K./ Inconnu
Ixodes pacificus	"	Southern B.C.[4]/ Sud de la C.-B.[4]	N.K./ Inconnu

* In ungorged state. The sizes vary for larvae, nymphs, and adult males and females./À l'état non gorgé; les tailles varient pour les larves, les nymphes, et les adultes mâles et femelles.
** N.K. = Not known.
***p.c. = personal communication./c.p. = communication personnelle.

The disease is seasonal, occurring during the warm months from May to August when ticks are active and outdoor activities such as camping, fishing and hiking are at their peak. In areas known to be endemic for Lyme disease, the following preventive measures can be taken: wearing clothing which provides adequate body coverage, periodic checking of clothing and exposed body surfaces

La maladie est saisonnière, les cas survenant pendant les mois doux (de mai à août) lorsque les tiques sont actives et que les loisirs de plein air comme le camping, la pêche et la randonnée pédestre sont les plus populaires. Dans les zones d'endémie connues, les mesures de prévention suivantes peuvent être prises: porter des vêtements qui couvrent bien, vérifier périodiquement les vêtements et les surfaces

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of both humans and pets for ticks, and the immediate careful removal of any ticks that are found.

Early symptoms of the disease in 75% of cases include a slowly expanding red rash, erythema chronicum migrans (ECM), around the insect bite[9]. Later symptoms in untreated cases involve the heart, nervous system, or joints. Any combination of the following 5 features can contribute to the diagnosis: exposure history, presence of ECM, neurologic, cardiac or joint symptoms, history of a tick bite, and serologic status. In any individual case, several of these may be present. For example, in a recent Connecticut study, 79% of patients with arthritis did not report antecedent ECM, and only 61% of those with ECM were aware of a tick bite within 30 days of illness[1].

The disease is treatable with antibiotics. Oral tetracycline is recommended for patients with early manifestations; penicillin and erythromycin are also effective. Children and pregnant women should be treated with penicillin. Transplacental transmission of B. burgdorferi has been documented and may be associated with an increased risk of adverse pregnancy outcome. Penicillin is recommended for the treatment of established arthritis[10].

corporelles exposées (tant chez les humains que chez les animaux), et enlever sans tarder et avec soin toute tique décelée.

Dans 75% des cas, les symptômes précoces de la maladie comprennent une éruption rouge, l'érythème chronique migrant (ECM), qui s'étend lentement autour de la piqûre d'insecte[9]. Dans les cas non traités, les symptômes tardifs se situent au niveau du coeur, du système nerveux ou des articulations. Toute combinaison des 5 éléments suivants peut contribuer au diagnostic: antécédents d'exposition; présence d'ECM; symptômes neurologiques, cardiaques ou articulaires; antécédents de piqûre de tique; et état sérologique. Tout cas particulier peut présenter plusieurs de ces éléments. Ainsi, dans une étude menée récemment au Connecticut, 79% des patients atteints d'arthrite n'avaient signalé aucun antécédent d'ECM, et seulement 61% des sujets avec ECM avaient une notion de piqûre de tique dans les 30 jours précédant la maladie[1].

La maladie peut être traitée par des antibiotiques. La tétracycline orale est recommandée au stade précoce; la pénicilline et l'érythromycine sont aussi efficaces. Les enfants et les femmes enceintes doivent être traités par pénicilline. La transmission transplacentaire de B. burgdorferi a été documentée, et est peut-être associée à un risque accru d'issue défavorable de la grossesse. La pénicilline est recommandée au stade des arthrites[10].

Table 2. Indigenous Cases of Lyme Disease Diagnosed in Canada, 1977-1986/
Tableau 2. Cas indigènes de maladie de Lyme diagnostiqués au Canada, 1977-1986

Case No./ N° du cas	Onset of Illness/ Installation de la maladie	Age (years) and Sex/ Âge (ans) et sexe	Where Infection Acquired/ Endroit	Information Source/ Source d'information	Confirmation Criteria and Methods/ Critères et méthodes de confirmation
1	October/ Octobre 1977	13F	Chatham, Ontario	J.E. Boone, London, Ont.: p.c.*, 1988; Ref. 11/J.E. Boone, London, Ont.: c.p.*, 1988; réf. 11	Clinical diagnosis (rash on thigh, fever, polyarthritis of knees and wrists) / Diagnostic clinique (éruption à la cuisse, fièvre, poly-arthrite - genoux et poignets)
2	1979	24M	Simcoe Area, Ontario (exposed summer 1978)/ Région de Simcoe, Ont. (exposition: été 1978)	Dr. Yadav, North Bay, Ont.: p.c., 1988/ Dr Yadav, North Bay, Ont.: c.p., 1988	Clinical diagnosis (knee arthritis) ELISA**, Dec. 1987 (+)***/ Diagnostic clinique (arthrite - genou) ELISA**, déc. 1987 (+)***
3	August/ Août 1983	8M	Pigeon Lake, Ont.	Ref. 12/ Réf. 12	Clinical diagnosis/ Diagnostic clinique
4	Summer/ Été 1984	53F	Chicoutimi, Quebec/ Chicoutimi (Québec)	Ref. 13/ Réf. 13	Clinical diagnosis (ECM, bite, meningeal lymphocytic reaction) indirect IFA† (+)/ Diagnostic clinique (ECM, piqûre, réaction lymphoméningée) IFA† indirecte (+)
5	November/ Novembre 1985	8F	Huntsville area, Ontario/ Région de Huntsville, Ontario	Ref. 14; Dr. H. Artsob, Toronto, Ont.: p.c., 1988/ Réf. 14; Dr H. Artsob, Toronto, Ont.: c.p., 1988	Clinical diagnosis ELISA (+)/ Diagnostic clinique ELISA (+)
6	1986	64F	Dryden, Ontario	Dr. L. Skela, Winnipeg, Man.: p.c., 1988/ Dr L. Skela, Winnipeg, Man.: c.p., 1988	Clinical diagnosis (rash, etc.) indirect IFA (+)/ Diagnostic clinique (éruption, etc.) IFA indirecte (+)
7	1986	66F	Thunder Bay, Ontario	Dr. Notenboom, Toronto, Ont.: p.c., 1988/ Dr Notenboom, Toronto, Ont.: c.p., 1988	Clinical diagnosis (tick bite, rash, neuritis) ELISA (+)/ Diagnostic clinique (piqûre de tique, éruption, névrite)

* p.c. = personal communication./c.p. = communication personnelle.
** ELISA = Enzyme-linked immunosorbent assay./ELISA = titrage immuno-enzymatique.
***+ = Positive./Positif.
† IFA = Immunofluorescence antibody./IFA = Immunofluorescence.

Thirteen human cases of Lyme disease were diagnosed in Canada between 1977 and 1987. Seven were indigenous cases (6 in Ontario and 1 in Quebec - Table 2) and 6 were acquired outside the country - 4 in the United States, 1 in Germany[15], and 1 in Yugoslavia. The disease is not reportable in any of the provinces. Most of the 7 indigenous cases had confirmatory serology by either indirect immunofluorescence antibody (IFA) or enzyme-linked

De 1977 à 1987, on a diagnostiqué 13 cas humains de maladie de Lyme au Canada. Il s'agissait de 7 cas indigènes (6 en Ontario et 1 au Québec; Tableau 2) et de 6 cas contractés à l'étranger (4 aux États-Unis, 1 en Allemagne[15], et 1 en Yougoslavie). La déclaration des cas n'est obligatoire dans aucune des provinces. La plupart des 7 cas indigènes ont fait l'objet d'une sérologie de confirmation, soit par immunofluorescence indirecte (IFA), soit par titrage immuno-enzymatique (ELISA). Un de ces cas concernait un visiteur

immunosorbent (ELISA) assays. One of these cases was a visitor from France who acquired the infection while in Chicoutimi, Quebec[13]. All of the other 6 cases were Canadian residents.

Currently used laboratory tests, i.e., IFA and ELISA, for Lyme disease have their limitations. These tests can have low sensitivity especially in the early phases of the disease[1,10], and in cases treated with antibiotics early in the course of the illness[1]. In addition, variable specificity occurs[1] with frequent asymptomatic seropositivity reported[16]. Consequently, in all cases, clinical information is essential in the evaluation of laboratory results. Furthermore, because of the limitations of serologic testing, laboratory reports alone cannot be used for routine surveillance. However, since the clinical signs of the disease are non-specific, serologic testing is particularly useful in confirming clinically compatible cases from areas where Lyme disease is not known to be endemic. Isolation of the organism is also possible, but it is not routinely performed.

Serologic testing for evidence of Lyme disease in Canada is still not common. As awareness of this disease increases, it is anticipated that there will be greater demand by physicians for laboratory assistance in diagnosis. Evidence of this has already been noted at the Ontario Ministry of Health Laboratory in Toronto where the number of specimens submitted for serologic testing rose from 7 in 1985, to 12 in 1986 and 56 in 1987. (R.H. Notenboom, Toronto: personal communication, 1988). The 1985 and 1986 specimens were all seronegative but 5 (9%) of those submitted in 1987 were positive. In contrast, in 1986 in Connecticut, a known endemic area, the seropositivity rate was 24% in 5175 specimens submitted[1]. Some provinces have expressed interest in identifying endemic areas and in conducting serologic studies on individuals living in these areas. Such studies would improve the current understanding of the ecology, prevalence, and clinical aspects of Lyme disease in Canada.

Acknowledgement: The assistance of Dr. H. Artsob and M. Garvie of LCDC is appreciated.

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15. Salit IE et al. CDWR 1988; 14:31-34.
16. Fahrer H et al. Schweiz Med Wochenschr 1988; 118:65-69.

SOURCE: *Elly Bollegraaf, Disease Surveillance Division, Bureau of Communicable Disease Epidemiology, LCDC, Ottawa, Ontario.*

venu de France qui a contracté l'infection à Chicoutimi (Québec)[13]. Les 6 autres étaient tous des résidents canadiens.

Les tests de laboratoire (IFA et ELISA) actuellement pratiqués pour la maladie de Lyme ont leurs limites. Leur sensibilité peut être faible, tout particulièrement aux stades précoces de l'atteinte[1,10], et dans les cas où une antibiothérapie est amorcée tôt dans le décours de la maladies[1]. En outre, la spécificité est variable[1], et la séropositivité asymptomatique, fréquemment signalée[16]. Dans tous les cas, il est donc essentiel d'avoir des données cliniques pour évaluer les résultats de laboratoire, et, étant donné les limites des tests sérologiques, la surveillance de routine ne peut reposer uniquement sur les rapports de laboratoire. Les signes cliniques de la maladie étant aspécifiques, la sérologie est toutefois particulièrement utile pour la confirmation de cas qui, compatibles sur le plan clinique, sont enregistrés dans des régions où la maladie de Lyme n'est pas réputée endémique. Également possible, l'isolement du microorganisme n'est pas pratique courante.

La sérologie de détection de la maladie de Lyme n'est pas encore courante au Canada. Plus la sensibilisation à la maladie s'intensifiera, plus les médecins devraient recourir à l'appui des laboratoires à des fins diagnostiques. C'est ce qui se passe déjà à Toronto, au Laboratoire du ministère de la Santé de l'Ontario, où le nombre d'échantillons présentés pour sérologie est passé de 7 en 1985 à 12 en 1986, puis à 56 en 1987 (R.H. Notenboom, Toronto: communication personnelle, 1988). Les échantillons de 1985 et de 1986 étaient tous séronégatifs, mais 5 (9%) de ceux de 1987 se sont révélés positifs. Par contre au Connecticut, région d'endémie connue, le taux de séropositivité était de 24% pour les 5175 échantillons présentés en 1986[1]. Certaines provinces se sont dites intéressées à identifier les régions d'endémie et à mener des études sérologiques chez les habitants de ces régions. De tels travaux permettraient de mieux comprendre l'écologie, la prévalence et les aspects cliniques de la maladie de Lyme au Canada.

Remerciements: Nous tenons à remercier de leur aide le Dr H. Artsob et M. Garvie du LLCM.

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SOURCE: *Elly Bollegraaf, Division de la surveillance des maladies, Bureau de l'épidémiologie des maladies transmissibles, LLCM, Ottawa (Ontario).*

QUARANTINABLE DISEASES REPORT/RAPPORT DES MALADIES QUARANTENAIRES

Week Ending: May 28, 1988/Semaine se terminant le: 28 mai 1988

Cholera/Choléra	Yellow Fever/Fièvre jaune	Plague/Peste
Infected Areas/ Régions infectées	Infected Areas/ Régions infectées	Infected Areas/ Régions infectées
Angola	Bolivia/Bolivie	Bolivia/Bolivie
Benin/Bénin	Brazil/Brésil	Brazil/Brésil
Burkina Faso	Burkina Faso	Equador/Équateur
Burundi	Colombia/Colombie	Madagascar
Cameroon/Cameroun	Gambia/Gambie	Peru/Pérou
Equatorial Guinea/Guinée Équatoriale	Ghana	Tanzania/Tanzanie
Ghana	Guinea/Guinée	Uganda/Ouganda
Guinea/Guinée	Liberia	Vietnam Soc. Rep./ République socialiste du Viêt-Nam
India/Inde	Mali	Zaire/Zaïre
Indonesia/Indonésie	Mauritania/Mauritanie	
Iran	Nigeria	
Ivory Coast/Côte-d'Ivoire	Peru/Pérou	
Liberia	Sudan/Soudan	
Malaysia/Malaisie	Zaire/Zaïre	
Mali		
Mauritania/Mauritanie		
Nigeria		
Rwanda		
Sierra Leone		
Singapore/Singapour		
Tanzania/Tanzanie		
Thailand/Thaïlande		
Vietnam Soc. Rep./ République socialiste du Viêt-Nam		
Zaire/Zaïre		

WHO reports cholera epidemic in Angola - 11 000 cases. Although cholera vaccination is not required under WHO international health regulations, travellers to Southern Africa would be well advised to have a "cholera entry" in the vaccination book in order to avoid problems with local requirements./L'OMS signale une épidémie de choléra en Angola - 11 000 cas. Même si le vaccin anticholérique n'est pas exigé par le Règlement sanitaire international de l'OMS, on conseille fortement aux voyageurs à destination du sud de l'Afrique d'avoir une inscription pour le choléra dans leur carnet de vaccination pour éviter tout ennui avec les autorités locales.

No change in requirements for Certificate of Vaccination against Meningococcal meningitis for Saudi Arabia. Also advisable for Mozambique./Les exigences relatives au certificat de vaccination contre la méningite méningococcique s'appliquant à l'Arabie Saoudite sont inchangées. Elles sont aussi conseillées pour le Mozambique.

Announcement

EPIDEMIOLOGIC PRACTICES IN CANADA

"E P I C '8 8"

VIth Annual Course
21-26 August 1988
OTTAWA, Ontario

This course, sponsored by the Department of Epidemiology and Community Medicine, University of Ottawa, and the Bureau of Chronic Disease Epidemiology, LCDC, Health and Welfare Canada, is designed for physicians and other health professionals involved in the investigation, surveillance and control of environmental and occupational hazards. The focus will be on current issues in environmental and occupational epidemiology. Since topics and faculty are different from previous years, the course will be of interest to past participants. Continuing medical education credits are available for registered candidates.

For further information, contact **The Department of Epidemiology and Community Medicine, University of Ottawa, 451 Smyth Road, Ottawa, Ontario, K1H 8M5, (Telephone: (613) 737-6480).**

Annonce

PRATIQUES EN ÉPIDÉMIOLOGIE AU CANADA

"E P I C '8 8"

VIe cours annuel
Du 21 au 26 août 1988
OTTAWA (Ontario)

Coparrainé par le Département d'épidémiologie et de médecine sociale de l'Université d'Ottawa et le Bureau d'épidémiologie des maladies chroniques du LLCM (Santé et Bien-être social Canada), ce cours s'adresse aux médecins et autres spécialistes de la santé chargés d'analyser, de surveiller et de contenir les risques environnementaux et professionnels. L'accent sera mis sur les questions d'actualité en épidémiologie professionnelle et environnementale. Les sujets traités et les membres du corps professoral n'étant pas les mêmes qu'au cours des années précédentes, le cours intéressera les anciens participants. Le cours sera donné en anglais seulement. Des crédits en formation médicale permanente sont offerts aux candidats inscrits.

Pour plus de renseignements, s'adresser au **Département d'épidémiologie et de médecine sociale, Université d'Ottawa, 451, chemin Smyth, Ottawa (Ontario), K1H 8M5, (Téléphone: (613) 737-6480).**

The Canada Diseases Weekly Report presents current information on infectious and other diseases for surveillance purposes and is available free of charge upon request. Many of the articles contain preliminary information and further confirmation may be obtained from the sources quoted. The Department of National Health and Welfare does not assume responsibility for accuracy or authenticity. Contributions are welcome (in the official language of your choice) from anyone working in the health field and will not preclude publication elsewhere.

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Circulation: Dolly Riggins (613) 957-0841

Bureau of Communicable Disease Epidemiology
Laboratory Centre for Disease Control

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CANADA 150

OTTAWA
April 12, 2017

Hon. Minister Philpott
Minister of Health
Hon.Jane.Philpott@Canada.ca

Dear Honourable Minister,

At a meeting in my Ottawa office today, I had the honour of hearing from Sue Faber and Jennifer Kravis of LymeHOPE who delivered a message of desperation on behalf of tens of thousands of Canadians suffering with Lyme Disease.

These two remarkable women are compelled by a sense of moral obligation to raise awareness of this health crisis and to bring it to the attention of the Nation's Health Minister.

I have also heard from constituents in my riding of Saskatoon – Grasswood who are suffering unimaginable hardships due to lack of proper diagnosis and treatment.

This is a critical time as I am sure you are aware because the proposed Draft Federal Framework document is considered by many to be void of the crucial input of medical and scientific experts and patients to make it optimal.

What is clear is that there is a lot of suffering and hardship and it is incumbent upon us all, as leaders, to hear what Canadians are telling us and to act in their best interest.

I encourage you to meet with Jennifer Kravis and Sue Faber to hear, in their words, the insurmountable obstacles faced by Lyme Disease sufferers across Canada, to help inform your policy decisions. You would not regret the time spent listening to these women. Their knowledge and humanity is an invaluable contribution to this important discussion.

Sincerely,

Kevin Waugh, MP
Saskatoon – Grasswood

C: Sue Faber
Jennifer Kravis
Marilyn Hamoline

The Honourable Jane Philpott, Minister of Health

If you are reading this it means I was able to personally speak with you and for this I am grateful. I can see from your Bio that you have spent a good portion of your life serving and helping others. I see you are a co-founder of TEDxStouffville, a wonderful accomplishment. I encourage you to watch any of the several TEDx talks available regarding Lyme Disease. Congratulations on your appointment in 2015 to the Minister of Health, an honour indeed, and one that comes with great responsibility.

I will try to keep our story brief, but please know that our story mirrors thousands of others

In 2005, my then 6 year old son presented with a bulls eye rash. I took him to our local ER, he was treated for an infected insect bite (topical cream) and sent home. I have since come to learn that a bulls eye rash is a definitive, classic clinical Lyme symptom. Throughout his public school years, his health began to decline. First, what appeared to be perhaps allergies (sinus issues, repeated ear infections and strange rashes popping up all over his body. Then his eyes began to bother him, swollen, dry, red, light sensitivity, blistering (by 2012 he was alternating an eye patch daily for relief), constant ringing in his ears, cyclical mouth sores, anywhere between 5 and 20 on his tongue gums and cheeks at the same time, breaking teeth and his joints began to randomly swell, were red and hot to the touch. He also began to have severe constipation issues resulting in 2 deep fissures which continue to bleed and cause him pain to this day. He began to have stabbing sensations throughout his body and was gaining weight rapidly despite a continuing decline in appetite (dizziness,nausea and heartburn would plague him daily now). His final year of public school was agonizing for him as he tried to attend every day despite the now crushing fatigue and insomnia that had set in. At my urging, he was able to attend 30 minutes of his grade 8 graduation and then asked me to take him home. The blisters on his eyes were bleeding, and as he had now developed a strange symptom of soaking sweats both day and night, he was embarrassed to be there any longer.

He began to appear increasingly confused over those early years, his short term memory became severely impaired as well as it became increasingly painful for him to walk. Obviously, we had been to several drs over this time, he had been diagnosed with depression, was prescribed fluoxetine and he began to see a therapist. The year 2013 was a turning point for us. I could no longer accept that these mounting, strange symptoms were not related. My once joyful, social, funny, active boy became someone I did not recognize. He had gained over 100 lbs, loud sounds jolted him, was experiencing panic attacks, had daily excruciating pain that moved around his body, stabbing and burning sensations, stiff neck, headaches, random numbness and subtle tics that had presented over the years (eye blinking, throat clearing, toe walking, repetitive movements). It was however, in the summer of this year that the vocal tics began. Quiet at first, he would go to his room and “release the tic” but very rapidly escalated to loud uncontrollable tics that saw no reprieve.

He was experiencing severe depersonalization (he would comment he felt like a floating leaf). He began to wet the bed. He was now having terrifying nightmares, suicidal thoughts and slept with a knife under his bed for protection. My nights were spent laying on his floor, paralyzed with fear that he would awake and harm himself. I thanked God over and over that my child shared these intrusive thoughts with me and asked me for help. He knew these dark thoughts were not right or true. All the while we continued with therapy. As a Mother I suspect you can empathize that it is difficult for me to revisit that time at all, my heart breaks to recall any of it.

After seeing 15+ specialists, he had now been diagnosed with chronic blepharitis/conjunctivitis, chronic constipation (Crohns had been ruled out however an MRE did reveal inflammation), Tourettes Syndrome, Chronic Fatigue Syndrome as well as his Ferratin was consistently low and his CRP elevated. He spent most of his days sick in bed. He had developed an odd rash that year, over 30 elevated, purplish spots that were on his legs from May to September. (Dermatology at Sick Kids Hospital Toronto suggested they were bugs bites slowly healing but could not explain to me why a healthy child would have the same bites for 5 months) He had a strange purple streak like rash on his back, stomach and back of his legs which I was told were stretch marks, a plausible explanation as he had gained so much weight. Unexplained, chronic and steady weight gain can be a symptom of Lyme Disease, caused by the affect the pathogens have on the patient's metabolic system. Dr Ronald Murphy, a Pediatrician in Orangeville On suggested my son use a smaller plate when eating. When I reminded him that he was barely eating he looked my son square in the eye and said "well when you do eat, put it on a smaller plate" and walked out of the room. My son was devastated and ashamed. I now know those "stretch marks" were a common symptom and indication of a Bartonella infection. Dr Karen Liquornik, a pediatric GI in Newmarket On suggested my son was sneaking food in the middle of the night, that although he did have symptoms resembling Crohn's Disease (Lyme Disease is known as "The Great Imitator") she could not find anything remarkable by scope and therefore it must be psychosomatic and recommended he be placed in the Holland Bloorview Rehabilitation Hospital where they "promote life skills where clients learn to function optimally within their home and community". Dr Peter Church, Pediatric GI at Sick Kids Hospital Toronto diagnosed my son with chronic constipation and told him "thousands of people live with this and you will figure how to as well". Please understand that my son had rectal bleeding through his clothes daily at this time. Bless our Nurse Practitioner, despite being assured by others these symptoms were isolated from one another, she continued to believe this was a systemic issue, and encouraged me to keep looking. That fall, I happened upon a U.S. news programme and watched an interview with a young man who was being treated for Lyme Disease and Co-Infections. His story mimicked ours almost verbatim, I recalled the bulls eye rash from years ago and so began our journey into this misunderstood, underestimated, underreported, debilitating and politically charged issue.

While I appreciate the efforts of Sick Kids Hospital in particular, I am curious to understand why, when I was now presenting this information to Gastroenterology, Clinical and Metabolic Genetics, Immunology, Ophthalmology, Neurology and Rheumatology, each of these departments relies on serological tests and assured me that as my child's ELISA was negative, he did not have Lyme Disease. With classic symptoms and a bulls eye rash.

It was odd to me at the time, but there was one MD in Rheumatology who quietly pulled me aside as I was leaving the appointment, and although she would not say the word “Lyme” she did say “that thing you were asking about - pursue that road further”. I now realize she was protecting herself by having this clandestine exchange with me.

I am a Mother, a Real Estate Professional, a taxpayer and a proud Canadian. Prior to my son becoming homebound, I spent many years volunteering at my local food bank. I believe we should all help each other, we can make a difference in others lives and we should always share our blessings. I suspect you feel the same way and that is why you threw your hat in the political ring. I admire that.

I have always felt very fortunate to live in a country that cares about the health of all Canadians and as such, believes in the value of public healthcare for all. I must admit Minister, that over the last few years, I, my family and those around me have become very discouraged by the lack of knowledge, education, awareness, or even acknowledgement by our Government regarding these infections. Yes, I am aware of the Federal Framework on Lyme Disease held this past May and I am aware of the results of that thus far. I am also aware of the heartbreaking stories of so many other Canadians that need help now, in real time. My son is blessed that he has a supportive family that is able to tap into resources to help him that many, many other folks are fiscally unable to do. Every day I think about the helpless children in my wonderful country who have been infected and there is quite simply nowhere for their parents to turn for help. My heart breaks daily for each and every one of them, and I wish I could help them all. I, unfortunately do not have that power, but thankfully, you do.

After 11 painful years my son, with the correct diagnosis and treatment, is now on his way to recovery. His eyes are completely healed, he no longer requires daily amounts of medication to move his bowels, his rashes when they do appear are less severe, the vocal tics are gone, the nightmares have vanished, insomnia has improved dramatically, his emotional health is strong, the physical tics have become far less frequent, he has returned to a normal, healthy weight. He still suffers greatly with pain and other issues, but we are moving in the right direction. He smiles again, he laughs. Slowly but surely, my son is coming back to me.

In closing I will leave you with a few questions that I pray you will give some thought to

Why are Canadians not educated on the possible devastating effects of these infections when not caught early? And why are the majority of our Dr’s unaware? Why are so many Dr’s afraid to even discuss the possibility of these infections lingering “post treatment”? Where is this fear coming from? Why are our pets treated more humanely than our citizens in regards to Lyme?

With never ending news reports on “trimming the fat” of our health care system, I wonder why this issue is not being looked at. The merry go round of well intended specialists the average Lyme patient sees prior to diagnosis is a complete waste of public tax dollars and could easily be saved with proper testing. Even Health Canada website acknowledges our testing lacks specificity, that this is a clinical diagnosis yet few are clinically diagnosed. I understand there is much to learn with these infections, however with over 700 peer reviewed scientific articles published surely we can do even marginally better than we are now.

As a Dr, knowing my son’s symptoms, with a negative ELISA test in Ontario, would you be comfortable encouraging him to donate blood? As his Mother, this will never happen as I have educated him on the risks of this action given so many unknowns regarding these infections.

Why as parents of sick children, are we ridiculed, written off, shamed (and in some cases reported) for trying to find help? And why is this abuse allowed to happen right in front of our children? Aside from the damage the infections are causing, what is the long term damage of our kids being treated this way? And what of the parents who are terrified to take their child to the ER as a result of these experiences?

If these infections are not congenital then why are the children of infected Mothers presenting with symptoms? Some even testing positive through the Public Health System?

As a taxpayer, I continue to see parents denied tax credits that other parents with children functioning at a higher level are granted. There is no one in the Lyme community looking for special treatment, however we do expect to be treated fairly.

I realize this is a hot button issue, and that the Lyme Community is routinely written off as being “mentally unstable”, however I assure you that if you look, you will find that the majority of us are actually quite stable despite being thrown into this surreal situation.

My son and many other children have already lost their childhoods to these infections, it is too late for them. I would assume that our Government would want to do everything possible to prevent one more child from suffering, especially given the fact that Lyme Disease is highly treatable with simple antibiotics when caught early.

Randy Shilts, author of the bestseller from 1987 And the Band Played On: Politics, People and the AIDS Epidemic, had this to say-”there was a threat to the nation’s public health that could no longer be ignored” “by the time America paid attention to the disease, it was too late to do anything about it. The virus was already a pandemic in the nation, having spread to every corner of the North American Continent. The AIDS epidemic, of course, did not arise full grown from the biological landscape; the problem had been festering throughout the decade. There had been a time when much of this suffering could have been prevented, but by 1985 that time had passed.”

I respectfully ask of you Minister Philpott, as a Canadian, a member of the Public Service sector, a Dr and a Mother to place a higher priority of urgency to this matter, and I thank you in advance, for all that you will do to help all Canadians live a happy, healthy, productive life.

Tamara S House
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MARC D. TARDIF
Mississauga, Ontario, Canada

June 3rd 2017

Dr. Jane Philpott
Federal Minister of Health
Via Lyme Letters Canada
PO Box 20045 Brant Hills PO
Burlington, Ontario
L7P 0A4

Via e-mail to lymeletterscanada@gmail.com

To Federal Minister of Health Jane Philpott:

Re: We Are All Just One Tick Bite Away From Being Too Young To Feel So Old

"You are too young!" is the one thing I keep hearing over and over again from the various medical doctors that I visit on a regular basis, which is something I do because I am afflicted with Lyme Disease. They believe I am too young to be spending the rest of my productive life on Long Term Disability. Too young to be taking so many pills and to be on a first name basis with my pharmacy owner. Too young to be hiring help for the simple domestic chores that I can no longer do. Too young to be stuck in the middle of life with my future behind me. Too young to be so actively preoccupied with estate planning matters and adding codicils to my ever-changing Last Will and Testament. Too young to be inquiring about euthanasia and having daily conversations with myself about why today is not a good day to die. Too young to have stopped dreaming and to have given up hope. Too young to feel so old.

My Lyme Disease journey started during the week of August 8th - 14th 2010, when I was 36 years young. My wife and I had rented a cottage near the town of Wingham in the county of Huron in the province of Ontario. While I was collecting dried wood for the fire we would have later that evening, I was bitten by a partially-engorged blacklegged tick. Only I did not know at the time that it was a partially-engorged blacklegged tick and that it was also a vector for a disease called "Lyme Disease". All I knew was that it was a weird-looking bug that I had never seen before and so I flicked it off and continued on with my task. **Having not immediately felt any ill effects from that bite**, I forgot about it entirely by the time our vacation ended and we returned to work. And about a month later, I started to experience symptoms of pain and fatigue accompanied by a general feeling of malaise. I was stumped as to the explanation for the sudden appearance of these symptoms, seemingly out of nowhere and for no obvious reason, and that is when my new career as a Lyme Disease patient started. Ironically, in my first career as a computer programmer, I was always looking for bugs in the code. As a Lyme Disease patient, it turned out that there was a bug in the programmer.

I believe it would be appropriate to provide objective definitions for the words "pain" and "fatigue" in the context of Lyme Disease since they are inherently subjective experiences and one's interpretation of "pain" and "fatigue" can be vastly different from another's interpretation of "pain" and "fatigue". In my case, and surely in the case of other patients in the chronic stage of Lyme Disease, my experience of "pain" is comparable to the kind of pain an average person would experience upon getting out of bed the morning after a day of **unusually strenuous physical activity**

such as, for example, running a marathon. That kind of pain and stiffness is worse during the morning, but for most people, as the hours and days pass, the pain gradually recedes and fades away into nothing more than a memory. Except that for me and other Lyme Disease sufferers like me, **that pain and stiffness never recedes and never fades into memory. It is always there and morning after morning, day after day, week after week, month after month, year after year, decade after decade, we always feel like we wake up each morning feeling like we have run a marathon the day before**. As for objective definitions of the word "fatigue", I ask you to remember when you last had the flu or some other illness that might have kept you in bed for a few days. Anyone who has experienced the flu can testify to the feeling of deep down fatigue that accompanies it and how trying to accomplish even the least demanding task such as putting away dry dishes can feel like a monumentally exhausting activity. So in addition to waking up each morning feeling like we have run a marathon the day before, **me and other Lyme Disease patients like me also wake up each morning feeling like we have the flu.** It is therefore easy for anyone to understand how difficult and debilitating it would be to go about the activities of daily living if you woke up each day with the flu and also feeling like you have run a marathon the day before. I hope that these common analogies help you to better understand and relate to the challenging experience of living each day with Lyme Disease.

During the past six and a half years, I went from doctor to doctor, trying to figure out why I was experiencing so much pain and fatigue. **I knew there was something wrong with me that was not wrong with others**, since they did not report the same pain and fatigue as I did from merely sitting at a computer and clicking the mouse all day long. Diagnoses of fibromyalgia, chronic pain disorder and depression emerged, and this put me in the path of all the pills that I still take to this day. Potent narcotic painkillers were included among those pills. Eventually I could no longer hold down my career and this put me into the unenviable position of battling the bureaucracy for the disability insurance benefits I desperately needed. With the help of a good Samaritan lawyer, I was able to finally collect those much-needed disability benefits. And then finally I was able to get to the last item on my medical to-do list, which was an expensive blood test for Lyme Disease through IGeneX Laboratories in Palo Alto, California. The positive result that emerged from those tests spurred a series of haphazard memory recalls that led me to finally remember that long-forgotten bite by that partially-engorged blacklegged lick in August 2010. Those positive test results, along with the memory of that tick bite and the interpretive help of research scientist John D. Scott from **LymeOntario.com**, helped to cement the diagnosis of Lyme Disease. And additional testing through the Public Health Ontario (PHO) laboratories revealed that **I also had a co-infection with *Coxiella burnetii*, the causative agent of a disease called "Q Fever"**. It is not uncommon for Lyme Disease patients to test positive for other tick-borne infections since "ticks are nature's dirty syringes" (John D. Scott 2017), sticking their needles into anything with blood. For the first time in a long time, I had hope that my miserable chronic pain and fatigue could eventually end. But I soon discovered that, in the province of Ontario at least, treatment for Lyme Disease seems hard to come by.

I soon learned to recognize the **fear on the faces of doctors** who heard me ask about testing and treatment for Lyme Disease. The fear in their faces is so easy to read. It is the fear of having to be involved in a very politically controversial disease and a potentially career-limiting if not career-ending decision to treat that disease. It is the same fear that goalies would have when players of the opposing team are skating towards them in a big hurry and with the sole intent of slamming that puck into their net. And so doctors have learned a few tricks to redirect or evade the Lyme issue altogether, with requests for testing and treatment being frequently met with speeches along the

lines of "it's all in your head", "Lyme Disease doesn't exist", "practice mindfulness", "stop looking for answers", "you'll never find the answer" and "just learn to live with the pain". Lyme Disease patients need treatment, not speeches. And when going from doctor to doctor in search of treatment, the answer often seems to be that there is some other doctor who would be able to do it instead of them, and so you end up getting stuck in a never-ending loop of chasing your own tail. And to add insult to injury, the Ministry of Health has recently released **updated opioid-prescribing guidelines** which have lowered the **"Watchful Dose"** from 200 mg of morphine or equivalent per day to 90 mg of morphine or equivalent per day. Many chronic pain patients currently on opioid therapy have been maintained at doses well above the "Watchful Dose Limit" of 90 mg of morphine or equivalent per day for years and must now contend with a drastic and sudden reduction in their morphine dosages. For the record, any chronic pain patient would tell anyone that "**we're not trying to get high, we're just trying to get by**" when asked about their usage of drugs such as opioid analgesics and medicinal marijuana. The goal of opioid therapy is to provide enough relief from crippling, debilitating and unrelenting pain so that patients can function to some extent in the activities of daily living. However, there currently exists no opioid-prescribing guidelines for Lyme Disease specifically, so the most widely-accepted interpretation by medical doctors of this lack of guidelines is "no narcotics for Lyme Disease patients". In my case, and surely in the cases of other Lyme Disease patients, **I have now lost the opioid pain medications that I depended on for years and my functioning in the activities of daily living has degraded significantly to the point of now being essentially bedridden.** My quality of life has been significantly reduced because of the introduction of these new guidelines. There exists no single word or even a combination of words that can accurately and completely describe this experience of profound unwellness and total misery to people who are fortunate enough to not know what it feels like to live in the body of a Lyme Disease patient. The result of day after day and week after week and month after month of lying in bed with the miserable coldness of unmanaged and soul-crushing chronic pain is the pervasive feeling of hopelessness and despair and the thought of eventually dying in this very deep hole. On some days I can even see the epitaph on my tombstone, inspired by Julius Caesar, which reads "he tried, he cried, he died". The only question seems to be "how soon"?

While on the subject of the paucity of actual Lyme Disease treatment in the province of Ontario, I would also like to point out the **need for more transparency on the specifications for the Lyme-related tests that can be ordered from the "Public Health Ontario" (PHO) laboratories (hereinafter referred to as "PHO tests" and "PHO reports").** The test results reports from IGeneX are very transparent. Their specifications are printed on the results reports themselves, and so you know exactly what criteria were used to render your results. However on the PHO reports, all you see are short phrases such as "Non-Reactive" or "No serological evidence of infection" without any mention of the criteria that were used to render those results. Calls to the PHO Customer Service Centre at 1-877-604-4567 for information on the specifications behind those tests are met with responses suggesting that we're on a "need to not know basis" as far as those specifications are concerned. From information I acquired by consulting various publications for laboratory professionals, it could be that one of the specifications for the PHO tests would be an **"elevated" level of antibodies to the *Borrelia burgdorferi* bacteria.** An "elevated" level of antibodies to the *Borrelia burgdorferi* bacteria would typically be seen in the **early stages of infection**, such as four to six weeks after the tick bite, and not in the later stages of infection when the symptoms have become chronic. "Elevated" could be defined to be high as or higher than the upper quartile, a scenario wherein 25% or less of the population would be expected to show positive. Or "elevated" could be defined to be high as or higher than the 90th percentile, a scenario wherein only 10% or less of the population would be

expected to show positive. Or "elevated" could mean something entirely different altogether. But one thing is for certain, and that is **that interpretations on the meaning of "Non-Reactive" or "No serological evidence of infection" can greatly vary from doctor to doctor.** Some will say that those phrases mean "you do not have Lyme Disease", others could say "it might be a false negative and we need to do repeat testing" and the rare few might correctly say that "the two-tier Lyme Disease serology is only 42% accurate 4-6 weeks after infection" (Stricker and Johnson 2014). And another thing is for certain, and that is that **a test intended to report positive only on recent infections would be inappropriate to use on patients who know that their infection is more than four to six weeks old**, just like a test intended to report positive only on older infections would be inappropriate to use on patients who know that they were bitten by a tick within the past four to six weeks. And so the correct interpretation of "Non-Reactive" or "No serological evidence of infection" on the current PHO reports might be more correctly worded as "No serological evidence of **recent** infection", which would not necessarily mean "you do not have Lyme Disease". **And it is for these reasons why I believe there needs to be greater transparency on the specifications for the PHO tests and more training so that doctors have a better idea on how to correctly interpret their results.**

The issue of Lyme Disease does not concern only the current Lyme Disease patients and their loved ones, it concerns every single one of us, infected or not. Any person who is not currently a Lyme Disease patient can easily become one in a matter of seconds. One is never too young, nor too old for that matter, to get sick from the prick of a tick. **We are all just one tick bite away from our lives being changed forever.** Just one tick bite away from a life of debilitating pain, fatigue and misery. Just one tick bite away from not being there for your loved ones. Just one tick bite away from being unable to hold down your career. Just one tick bite away from being thrown into legal conflicts with employers and disability insurance carriers. Just one tick bite away from going from doctor to doctor in your quest for an answer to the question of what is wrong with you that is not wrong with others. Just one tick bite away from being buried under a mountain of pills. Just one tick bite away from having to call on others for help. Just one tick bite away from being just a shadow of our former selves. Just one tick bite away from wondering if today is a good day to die. Just one tick bite away from so many other grim thoughts. Just one tick bite away to be too young for all that.

But it doesn't have to be that way. **For the sake of all of us, and I really do mean all of us and not just those of us afflicted with Lyme Disease**, I implore you to make every effort to **supply increased funding to the areas of Lyme Disease research, education, treatment and prevention.** With more information, people will become more aware. With more money, scientists can be hired. With more research, answers can be found. With more answers, treatments can emerge. With more studies, vaccines can be discovered. With more action, hope can once again be ours.

Signed most sincerely,

Marc D. Tardif
MDT/mdt

Alison Tardif
Mississauga, Ontario

June 3, 2017

Dr. Jane Philpott,
Federal Minister of Health
Via Lyme Letters Canada
Via e-mail to lymeletterscanada@gmail.com
PO Box 20045 Brant Hills
Burlington, Ontario
L7P 0A4

Re: Our pet dogs are provided with better treatment for Lyme than Canadian citizens.

Dear Dr. Philpott:

In 2010 two of my precious family members were bitten with Lyme infected ticks. One was my husband Marc and the other was our dog Kenny. Only one of these individuals was promptly and appropriately screened and effectively treated with antibiotics and he made a full recovery from Lyme disease and that family member was our pet dog. At that time Kenny's Veterinarian in Mississauga advised us that the geographical area in which we live and the surrounding areas are filled with Lyme-positive ticks and that he had seen a marked increase in dogs having ticks removed which tested positive for Lyme disease. We knew what those implications meant because where our dog went, we went.

Lyme disease is an inflammatory disease transmitted by tick bite. It is a bacterial infection that can lead to neurological, cardiac and other complications and early death, especially when left undiagnosed and untreated.

I personally endorse the commitment of our Veterinarian clinic of holding themselves to the highest standard. Pets are their passion and keeping them healthy is their #1 priority. They strive to deliver excellent care for pets because our pets deserve nothing less.

I wholeheartedly agree. Our pets deserve the best possible care throughout their lifetime and so do our pets' people. **It's frightening that the same standard of care used to treat Lyme infected dogs <u>does not</u> exist for Lyme infected humans in Ontario.** I can't believe I have to spell this out so plainly: If it is good enough for our Canadian dogs it needs to be good enough for our Canadian people. What could be more important?

The Mississauga News ran a front-page article on March 2, 2017 called **<u>The Waiting Game</u>**. In this article, Marlene Spies, 55 casually asked a veterinarian some years ago if he would test an acquaintance of hers for Lyme disease, as there's no accurate protocol testing for humans in Canada. The horrified vet refused to entertain the idea. Marlene Spies arrived at the same, unsettling observation as I have: that **dogs in Canada, could access more compassionate and better quality care than humans.**

Prior to suffering from chronic Lyme disease, my husband Marc was a fully functioning member of society. He worked full-time in a rewarding career. He paid taxes. He enjoyed good health and an active lifestyle. He helped with chores at home and he was a wonderful and good natured husband to me. Marc became infected with Lyme disease in the same year (2010) that I became permanently and totally disabled as a result of serious injuries caused when I was struck as a pedestrian by a speeding and distracted driver.

One person becoming disabled in a household is challenging. And two people becoming disabled simultaneously with chronic severe pain in a two-person household is just too overwhelming. Especially so when 50% of the household has a completely treatable tick-borne bacterial infection. I have watched in increasing horror as Marc's health, well-being and quality of life has eroded over the years. He endures worsening brain fog, joint and muscular-skeletal pain, cold-intolerance, hormonal imbalances, thyroid dysfunction, erectile dysfunction, early onset male menopause, depression, anxiety, fear, frustration, bad-mood, anger, and chronic exhaustion and feelings of inadequacy. There is no fun or enjoyment or quality in Marc's (or my) life. It's a struggle to just make it through the day let alone navigate our failing healthcare system.

The economic, physical and emotional strain this has placed on our marriage of 16 years is staggering. We are constantly living in a state of uncertainty that at any moment at the whim of our LTD (Long Term Disability) Insurers' we may lose our source of already reduced disability incomes. That scenario is scary enough when it affects one family member but when it affects both it is truly life-altering in its magnitude. **Still we would rather give up every last penny we have if it meant we could be returned back to healthy, productive members of society.**

We also live in fear that even if we can against all odds find a Dr. to treat Marc whether it be locally (unlikely) or abroad (USA) that his chronic Lyme disease may be too far advanced to remedy. Some medical literature suggests that when Lyme is left untreated for a long period of time, in some patients the condition might not be reversible. If that proves to be the case for Marc that would bad, very bad.

The ultimate irony is that opioid narcotic pain medications which only masks Marc's symptoms have been much easier for him to receive from his Doctors than the as yet impossible to obtain necessary antibiotics or any other Lyme treatment. Narcotics in addition to certainly causing physical dependence and potentially causing psychological addiction do not treat the underlying and worsening disease, they only mask the symptoms and very temporarily ease Marc's debilitating pain. Unlike narcotics, antibiotics are not addictive and don't cause physical dependence yet Lyme patients are being barred access to this treatment at every turn. This **gross negligence** makes no sense to me**. We don't refuse treatment to people with illnesses such as diabetes, heart disease or cancer** so why should it be any different for people who had the misfortune to become ill from a tick borne infection?

To further complicate matters, The Liberal Government has decided to handle the "Opioid Crisis" by cruelly and needlessly punishing legitimate and medically supervised chronic pain patients effective March 2017 by:

1. Mandating a huge reduction of opioid dosages for the small percentage of individual pain patients that qualify for continuation of their opioid therapy.

2. Mandating a complete stoppage of opioid therapy for Marc which was freely prescribed by his pain management Doctor over the past 5 years but effective immediately is **no longer indicated for the treatment of Lyme disease.**

This new mandate really leaves Marc and others like him in a very dire situation. He is now frequently bedridden and experiencing inadequate pain control and he still has no access to the appropriate Lyme treatment he needs to mitigate the underlying infection and the resultant pain. Marc is but a shadow of his former self and I am afraid that if things continue to get bad enough he may take his own life and I really can't say I would blame him for doing so.

I don't want to lose my husband to a preventable suicide nor do I want to stand by and helplessly watch him continue suffering as Lyme chips him apart one piece at a time. A death by a thousand cuts is absolutely cruel and unacceptable especially when Lyme is a treatable illness. This is something we might expect to face in a third world poverty stricken country but this should not be happening in this magnificent country of Canada into which we were born and raised and proud to call home. This lack of treatment for Lyme is nothing to be proud of rather it is a downright embarrassment. Please help us before it is too late. We didn't ask for this and **we are asking for access to treatment** even if it means we have to pay for it out of our own limited pockets.

Why doesn't the Ontario testing protocols for Lyme include screening for chronic / older infections instead of only screening for very recent infections? Most people with Lyme and other tick-borne co-infections do not even realize there is a problem until it gets to the chronic worsening stage. And unfortunately even then it mostly goes undiagnosed. In June 2016 it was only in sheer desperation we decided to send Marc's blood samples to IGeneX Inc. Laboratories in Palo Alto California for 6 Lyme testing panels. When his results came back positive for an older Lyme infection we felt it was well worth the $860.00 we paid out of pocket to finally know what was causing Marc's illness and to finally feel validated and hopeful. Our mood plummeted from hopeful to devastated when we started knocking on physicians doors only to have them slammed in our sad faces. With each subsequent Doctor Marc is sent to, he is told that it always some other elusive Doctor who is supposed to be treating his Lyme. It's never the current Doctor. We found out we could not obtain any treatment in Canada. If only we could put Marc into a cute doggie outfit.

Medical Schools administer the Hippocratic Oath upon graduation. All physicians at the beginning of their bright careers in medicine swear among other things to do no harm to their patients (see appendix 1). Yet for some perplexing reason Doctors are acting in direct contravention of their oaths by refusing to treat Lyme infected Canadians.

Dr. Philpott please put yourself in my position. How would you feel if this was your spouse or your children or your parents or **you** in this predicament of being struck down with Lyme disease with no access to the treatment you so desperately need. How would it make you feel to be told by your Doctors that there are simply no Doctors that will treat Lyme disease in Canada? And to top it off how would you like your various treating physicians to cast self-doubt by suggesting that perhaps it is all in your head and you need to stop looking for answers and stop chasing red herrings and just woman-up or man-up? God forbid this could be you or your loved ones in the future and should that time come you, like us, will wish you had the same level of care and treatment for Lyme disease that your pet dog received for the exact same illness.

Sincerely,

Alison Tardif

Appendix 1: Hippocratic Oath

From Wikipedia, the free encyclopedia

Modern version

I swear to fulfill, to the best of my ability and judgment, this covenant:...

I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.

I will apply, for the benefit of the sick, all measures which are required, avoiding those twin traps of overtreatment and therapeutic nihilism.

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

I will not be ashamed to say "I know not," nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery.

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. Above all, I must not play at God.

I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

I will prevent disease whenever I can but I will always look for a path to a cure for all diseases.

I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.

If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help.

Written in 1964 by Louis Lasagna, Academic Dean of the School of Medicine at Tufts University, and used in many medical schools today.

"First do no harm"

It is often said that the phrase "First do no harm" (Latin: *Primum non nocere*) is a part of the Hippocratic oath. The phrase as such does not appear in the oath, although the oath does contain Latin: *... noxamvero et maleficium propulsabo* (Also ... I will utterly reject harm and mischief).[6]

The phrase "primum non nocere" is believed to date from the 17th century (see detailed discussion in the article on the phrase). Another equivalent phrase is found in Epidemics, Book I, of the Hippocratic school: "Practice two things in your dealings with disease: either help or do not harm the patient".[7] The exact phrase believed to have originated with the 19th-century surgeon Thomas Inman.[8]