

EXAMINATION OF PETITIONS ON INTRODUCING AND IMPLEMENTING A LYME DISEASE ACTION PLAN



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INTRODUCTION

On February 20, 2018, under National Assembly Standing Orders 64.3 and 64.4, the Committee on Health and Social Services met to examine petitions No. 4028-20180207 and No. 4029-20180207. Pursuant to Standing Order 64.6, it resolved to hold special consultations and public hearings on introducing and implementing a Lyme disease action plan. On March 22, 2018, it heard Lyme disease expert, Dr. and Professor Christian Perronne, the Association québécoise de la maladie de Lyme, the Institut national de santé publique du Québec and Québec's National Public Health Director.

These organizations were represented by the following:

- Association québécoise de la maladie de Lyme
 - o Mrs. Marguerite Glazer, AQML President;
 - o Dr. Christian Perronne, Chief, Infectious Diseases, Raymond Poincaré University Hospital, Garches; Professor, Faculty of Medicine, Paris-Ile de France-Ouest;
 - o Dr. Ralph Hawkins, Site Lead, General Internal Medicine, South Health Campus, Calgary;
 - o Professor Vett Lloyd, Professor and Lead Researcher, Lyme Research Network; Professor, Department of Biology, Mount Allison University.
- Institut national de santé publique
 - o Dr. Patricia Hudson, Scientific Director, Bio-Risk and Occupational Safety Department;
 - o Dr. Jean Longtin, Medical Director, Québec Public Health Laboratory;
 - o Dr. Alejandra Irace-Cima, Medical Specialist, Public Health and Preventive Medicine.
- Québec's National Public Health Director
 - o Dr. Horacio Arruda, National Public Health Director;
 - o Dr. Louise Valiquette, Medical Coordinator, Public Health Directorate;
 - o Dr. Jean Longtin, Medical Director, Québec Public Health Laboratory.

This report summarizes discussions between the participants and the Committee and sets out the Committee members' conclusions and recommendations.

DISCUSSIONS BETWEEN THE PARTICIPANTS AND THE COMMITTEE

Discussions between the experts that testified before the Committee on Health and Social Services (participants) and the Committee members addressed two main themes: defining the problem and seeking solutions.

The participants began by reporting on the issues linked to Lyme disease. The medical issues include the fact that knowledge about the disease and the disease's inherent complexity make diagnosing and treating it difficult. The human and social issues include the fact that patients with Lyme disease are forced to travel between health care services, generating unanticipated emotional, social and economic costs. Moreover, far from abating, the risks associated with Lyme disease are growing with the proliferation of ticks carrying bacteria that are harmful to humans.

These discussions led the MNAs to clearly define the issue and target solutions that can be envisaged for fighting the disease more effectively. Many of the comments made revolved around the need for intensifying research on syndromes linked to tick bites. Both those who testified and the MNAs stressed the importance of increasing efforts to raise awareness about Lyme disease among the public and among health professionals.

DEFINING THE PROBLEM

Medical issues

A complex disease that is poorly understood

Lyme disease is caused by the *Borrelia burgdorferi* bacterium, transmitted through the bite of a carrier tick. In the early stage, the infection presents an erythema migrans, or bulls-eye rash, at the bite location. Other symptoms resemble the flu: fever, sore muscles, headache, fatigue, etc. Left untreated, Lyme disease can cause severe complications as well as neurological, cardiac and joint damage. Like the initial symptoms, the disease's manifestations in the advanced stage are easily confused with those of other diseases, leading French researcher Dr. Christian Perronne to call Lyme disease the “great imitator”. Like syphilis in the past, it presents a diagnostic challenge for health professionals, given that its symptoms, especially in the advanced stage, are often difficult to identify. Dr. Perronne is surprised that the existence of a chronic form of the disease is contested by an influential part of the medical community since numerous studies show the persistence of *Borrelia* bacteria in animals, even after four months of

antibiotic treatment. In response to the Committee members' questions in this regard, all participants acknowledged that the workings of Lyme disease are complex and still poorly understood.

Serology

Both Dr. Perronne and Dr. Hawkins stated that the situation is exacerbated by flawed serological testing. Under current Canadian guidelines, two serological tests now supplement the clinical diagnosis. If a patient's first test (ELISA) is positive, the sample is re-tested (Western Blot, followed by a Line Blot test, if required) to confirm the result. This testing protocol complies with Infectious Diseases Society of America (IDSA) guidelines. However, according to the Association québécoise de la maladie de Lyme (AQML) and its experts, IDSA guidelines are increasingly being challenged in the United States and Europe. Recent scientific studies tend to invalidate the alleged sensitivity and specificity of the serological tests recommended for supporting Lyme disease diagnoses. Dr. Hawkins affirmed that research has shown that the ELISA detects only 64% of cases of the disease and the confirmation test unduly eliminates 50% of infected patients. Thus, by relying on laboratory tests to support their clinical diagnosis, health professionals who follow the current protocol may well diagnose only one-third of actual cases of infection. Consequently, Dr. Perronne and Dr. Hawkins stressed the importance of the physician's clinical diagnosis.

Treatment

Borreliosis – an infectious disease caused by *Borrelia* bacteria – is treated with antibiotics, generally prescribed for two to four weeks, depending on the patient's condition. Intravenous treatment for an extended period may be necessary if the disease is in an advanced stage. If the patient presents an erythema migrans and was infected in a location considered high-risk, the Institut national de santé publique recommends preventive antibiotic treatment. However, if the disease is detected at a later stage, antibiotic treatment often proves ineffective. Most of those who answered the survey conducted by the Association québécoise de la maladie de Lyme in preparation for the Committee hearing said they experienced little or no improvement in their health status after taking antibiotics as per the guidelines in effect. This tends to confirm Dr. Perronne's assessment that, while the short-term treatment works when administered promptly, it is generally ineffective for patients who have had the disease for a long time. In such cases, sequential treatments over many months, even years, prove necessary. Yet, current guidelines do not provide for such measures because, as Dr. Longtin pointed out, the data available to researchers do not show that prolonged antibiotic treatment is beneficial.

Social issues

Health professionals' inadequate knowledge about Lyme disease and ineffective diagnostic and therapeutic protocols cause many patients physical suffering, which is equalled only by the emotional anguish of travelling from doctor to doctor in the hope of obtaining an accurate etiology of their condition.

As the Association québécoise de la maladie de Lyme testified, most patients reported that they were dissatisfied by the medical care they received. The Committee members were keenly interested in this aspect of the issue. The majority of the AQML survey respondents said they felt misunderstood by the professionals they consulted in seeking a diagnosis and reported that they were misdiagnosed several times before getting an answer to their questions. Dr. Perronne and the Association québécoise de la maladie de Lyme recalled that such going from one health care service to another entails significant social and economic costs. The cumulative costs of the dramatic impacts experienced by these patients (work stoppage, job loss, separation, depression, etc.) entail social damages. Desperate, people with the disease sometimes feel forced to go abroad to seek a satisfactory diagnosis, incurring exorbitant costs. In the meantime, their comings and goings monopolize significant health care system resources: medical personnel, medication and therapists are all pressed into service to find a cure that is doomed to fail due to misdiagnosis.

Growing risk

These issues alone are a source of concern for the MNAs. However, the risk factor associated with them is multiplied by the situation described by Professor Vett Lloyd, Lead Researcher with Mount Allison University's Lyme Research Network, and by the Institut national de santé publique (INSP). The INSP, which is responsible for monitoring the disease in humans and ticks, reported that Lyme disease is gaining ground in Québec. Due to global warming and growing awareness on the part of health professionals, the number of declared cases has risen exponentially since 2010 and the territory considered "at risk" has expanded.

Professor Lloyd described the tick population in eastern Canada, providing insight into the reasons for its growth. She indicated that this population was increasing in number and variety because European and American tick species are carried by migratory birds crossing through Canada. Under a microscope, some of these insects – potential carriers of a European strain of Lyme disease – are impossible to distinguish from indigenous ticks. Current serological tests, which are already poorly calibrated to detect the North American form of the bacterium, are ineffective for identifying other strains.

Moreover, Professor Lloyd's laboratory has confirmed the presence, in Canada, of the bacterium *Borrelia miyamotoi*, which differs from *Borrelia burgdorferi*, causes symptoms very similar to those of Lyme disease and tends to reproduce exponentially. Professor Lloyd estimates that, whereas only 1% of ticks carried *Borrelia miyamotoi* in 2016, 4% are now infected, doubling their numbers annually over the last two years. This proliferation stems from the fact that this strain can be transmitted from an infected mother to her offspring. While ticks are the only known vector for *Borrelia burgdorferi*, *Borrelia miyamotoi* proliferates through reproduction, thereby significantly increasing its potential for propagation. Professor Lloyd also testified that serological tests are unable to detect this pathogenic agent effectively.

POTENTIAL SOLUTIONS

Intensifying research

The experts questioned by the Committee members felt that the complexity and poor understanding of Lyme disease and similar syndromes calls for further research. According to Dr. Perronne and Dr. Hawkins, many aspects of the disease require more in-depth study, for example, how the *Borrelia burgdorferi* bacterium is transmitted to humans. Further investments are needed to develop techniques for detecting the bacterium, and we must hone our knowledge of how to treat syndromes associated with tick bites. As with other aspects of the problem, physicians, researchers and veterinarians must collaborate to develop a vaccine that is safe for humans – currently, such a vaccine exists for animals. Finally, we need more specific knowledge about the ticks and bacteria themselves and how they proliferate and reproduce. According to Dr. Perronne, redefining the predominant paradigm for Lyme disease and other tick-borne infections would be facilitated if research projects were conducted in conjunction with a centre of expertise.

The Institut national de santé publique and Québec's National Public Health Director acknowledged that the protocol for treating Lyme disease patients can be improved. They agreed with the other experts the Committee heard on the need for more research on diagnostic laboratory tests and pointed out that the Ministère de la Santé et des Services sociaux (MSSS) mandated the Institut national d'excellence en santé et en services sociaux in September 2017 to make recommendations to health professionals on diagnosing, treating and monitoring Lyme disease. Dr. Horacio Arruda specified that this mandate entailed cross-referencing conclusive scientific data with patients' and health professionals' experiences to offset the lack of clear Lyme disease diagnosis and treatment guidelines and shed light on the scientific ambiguity surrounding the disease's chronic form.

Raising awareness

In answer to the Committee members' questions, the experts that testified concurred that public awareness-raising efforts must be increased and that the most sensitive areas and at-risk populations must be specifically targeted. Until there is a vaccine, public health authorities should give precedence to disseminating information on ticks, Lyme disease and good bite-prevention practices. Québec's National Public Health Director and the Institut national de santé publique said they were prepared to collaborate to improve current awareness-raising methods so as to reach more people, particularly those running the greatest risk of contracting the disease.

As all of the experts that testified before the Committee emphasized, it is also important to better inform health professionals about Lyme disease causes, symptoms, diagnosis and treatment. Over 4000

medical community stakeholders have already taken the Institut national de santé publique's training on Lyme disease, and the Institute will support all initiatives designed to increase that number.

CONCLUSIONS AND RECOMMENDATIONS

The Committee members said they were satisfied with the hearings, which they considered a major “wake-up call” to the ravages caused by Lyme disease, its complexity and the risks associated with it. The experts’ comments showed them that there are signs of a genuine public health problem. The Committee members are now more aware of the situation suffered by Lyme disease patients and wish to contribute to their well-being.

The Committee members see that there is no consensus in the scientific community on the causes and nature of Lyme disease. However, they note that rapid treatment increases the likelihood of recovery. Consequently, they stress the importance of intensifying research, ensuring that health professionals are better informed and raising public awareness of the risks, symptoms, means of prevention and treatment of the disease.

The Committee members acknowledge the measures established under the Ministère de la Santé et des Services sociaux (MSSS) and recognize the value of the monitoring, prevention and training carried out by the Institut national de santé publique. The Committee applauds the MSSS’s initiative to mandate the Institut national d’excellence en santé et en services sociaux to review the existing Lyme disease diagnostic and therapeutic protocol. However, the Committee members consider it pertinent for the Association québécoise de la maladie de Lyme to be closely associated with the Institut national d’excellence en santé et en services sociaux’s work and for that work to take into account the scientific literature which Dr. Perronne and Dr. Hawkins highlighted at the hearings. Finally, certain Committee members would like the MSSS to examine how the Association québécoise de la maladie de Lyme’s recommendations can be applied and would like the results of that examination be forwarded to it to be studied.

Recommendations

- 1. THAT the Ministère de la Santé et des Services sociaux implement a public awareness-raising campaign on the causes, symptoms and means for preventing Lyme disease by summer 2018. That this campaign focus on at-risk populations and that the MSSS submit a report on the communications strategy deployed to the Committee on Health and Social Services no later than December 31, 2018.**
- 2. THAT the Ministère de la Santé et des Services sociaux partner with the Institut national de santé publique to improve the training program for health professionals on the forms, diagnosis and treatment of Lyme disease as soon as possible.**

3. THAT, annually for the next three years, the Ministère de la Santé et des Services sociaux inform the Committee on Health and Social Services and the Association québécoise de la maladie de Lyme of the steps and actions to be taken based on the Committee's conclusions and recommendations, including the new means of treating chronic Lyme disease and the research component, based on the standards envisaged by the Institut national d'excellence en santé et en services sociaux.



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