

Multidisciplinary Roundtable Discussion on Lyme Disease

WebEx Meeting
Wednesday, October 24, 2018
1:00 – 3:00 PM EST

Information package for participants

Prepared by: Public Health Agency of Canada
November 19, 2018

Preface

This report summarizes information provided by participants of the Multidisciplinary Roundtable Discussion on Lyme Disease WebEx meeting as hosted by the Public Health Agency of Canada on October 24, 2018.

Information provided in this document is not intended to indicate consensus of opinion or agreement among participants on these topics.

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Infectious Disease and Climate Change Fund (IDCC Fund) Summary of Projects

More than \$2.1 million in funding under the IDCC Fund has been invested to support seven new Lyme disease Non-Government Organizations and provincially-led projects focussed on enhancing surveillance and monitoring efforts and developing new resources and tools for health professionals and the public. In addition, an eighth project submitted from the Government of Newfoundland and Labrador has recently been accepted. A full list of projects has been posted online at: <https://www.canada.ca/en/public-health/services/funding-opportunities/infectious-diseases-climate-change-fund.html>.

The following are brief descriptions of these projects, as provided by the lead organizations.

The Canadian Association of Schools of Nursing (CASN)

Empowering the next generation of health care professionals with knowledge, skills, tools, and supports to address infectious diseases related to climate change in Canada

Project summary: The goal of this project is to expand the scope of nursing education in Canada to better prepare future nurses to address health challenges related to climate-driven infectious diseases including zoonotic, food-borne, and water-borne diseases.

As part of this project, CASN will develop national, evidence-informed, education guidelines on climate-driven infectious disease for nursing educators and the undergraduate nursing programs. In addition, a series of accompanying online learning modules will support the education guidelines and provide high quality information and animated case studies in a dynamic, easy-to-use format.

CASN has set up a representative Advisory Committee to guide this project and will host a Stakeholders forum in the upcoming weeks. A successful kick-off meeting of the Advisory committee was held in Ottawa on October 18th.

If you would like more information about this project, please feel free to contact Kristine Crosby, Manager, Strategic Initiatives at kcrosby@casn.ca.

The Centre for Effective Practice (CEP)

Lyme disease toolkit

Project summary: Through the support of the Public Health Agency of Canada, the Centre for Effective Practice (CEP), in collaboration with the Canadian College of Family Physicians (CFPC), is developing a Lyme disease toolkit for use in primary care settings in Canada. Specifically, the toolkit will consist of two tools/resources that address the needs of target end users and the system overall related to Lyme disease. These tools include:

1. A clinical decision aid/tool intended for primary care providers (with a focus on family physicians and primary care nurse practitioners) that addresses challenges in Lyme disease diagnosis, treatment and patient conversations and;
2. A complementary resource for the patients that mirrors the provider tool, providing patient-tailored information and resources on Lyme disease diagnosis and treatment.

The CEP will leverage its rigorous tool development approach which includes extensive needs assessment and evidence review, iterative rounds of user-testing, and dissemination and evaluation planning.

This approach utilizes a co-design model, with a clinical lead and a working group comprised of target end-users, engaged throughout the process to ensure their input throughout the tool's development. In addition, a variety of engagement mechanisms will be leveraged over the course of the 16-month project to ensure appropriate stakeholder input.

For more information, please contact Matthew Gray by email at matthew.gray@cep.health or by telephone at (647) 260-7800, extension 303.

Mount Alison University
Led by Drs. David Lieske and Vett Lloyd

Field surveillance of tick populations through citizen science partnerships as means for acquiring high-density data community surveillance data and facilitating community education

Project Summary: This project stems from longstanding ties between individuals in communities with high tick densities in New Brunswick and Nova Scotia, and Mount Allison university researchers. A number of community members independently initiated their own tick monitoring in areas of importance in their neighborhoods, parks, school playgrounds, backyards, etc, and Dr. Vett Lloyd's research group have been working with them to provide advice, resources on tick identification, Borrelia testing and promotion of their work in other communities across the Maritimes.

Inspired by a 2017 publication reporting the formation of an impressive high density community-based tick surveillance network in the Netherlands (Garci-Marti et al. Int. J. Health Geog, 16(1):41), Drs. Lieske and Lloyd proposed to expand this network of community tick monitors across the Maritimes to generate high density longitudinal maps to monitor and predict seasonal tick prevalence in communities. We currently have 5 tick collectors who have been doing daily or weekly tick collections throughout the year for the past several years.

In 2019, we will be reaching out to others community members who have contacted us and will provide training in safe active tick surveillance, with the goal of covering all or most counties in both New Brunswick and Nova Scotia. We view this project as an opportunity to offer academic expertise in response to community needs to help support individuals and communities in the Maritimes in dealing with the increasing risk of tick-vectored diseases.

Please contact Dr. Vett Lloyd at vlloyd@mta.ca for more information.

Bishop's University
Led by Dr. Jade Savage

eTick.ca: a web platform for crowd-sourcing tick surveillance

Project summary: The eTick.ca web platform was created in 2014 by a team composed of members from Bishop's University, the Laboratoire de Santé Publique du Québec (LSPQ) and the Public Health Agency of Canada (PHAC). Pictures of ticks and associated collection data taken by the public are uploaded onto the web platform for image-based identification by an expert. Following identification, the data is instantaneously projected onto an interactive map, allowing visitors to visualize new records in real-time. Another important feature of the platform is that following identification, a message is automatically sent to the submitter providing the identification results and information of public health relevance specific to the species that was collected. The turn-over from submission to identification is generally less than 24 hours.

Following a pilot study aimed at testing the accuracy of image-based tick identification and the robustness of the online platform (Koffi et al. 2016), the public version of eTick.ca was launched in the province of Quebec in May 2017. In a context where the distribution of a number of tick species of medical relevance is rapidly changing, and numbers of Lyme disease (LD) cases keep on increasing year after year in Canada, deploying a monitoring and rapid information dissemination tool such as eTick.ca can increase public access to rapid identification resources, reduce the pressure on existing provincial surveillance programs, and standardized data collection across the country.

In spring 2018, Dr. Jade Savage (Bishop's University) and several collaborators secured three years of funding from PHAC's Infectious Diseases and Climate Change fund to further develop the eTick.ca platform and roll-out to additional provinces. Our specific objectives for this project are to:

1. Expand etick.ca services and resources in Quebec to Ontario and New Brunswick
2. Develop a new web interface and add new content
3. Develop a mobile application

The roll-out of the eTick.ca platform in Ontario and New Brunswick is planned for April 2019. The development of new content (e.g. awareness/prevention info, news, educational content) and province-specific requirements for Ontario will be a collaborative effort involving Dr. Savage (jsavage@ubishops.ca) and project coordinator Dr. Chuard (pchuard@ubishops.ca) at Bishop's University, provincial experts Drs. Claire Jardine (University of Guelph), Manisha Kulkarni (University of Ottawa), Stephen Heard and Joe Nocera (University of New Brunswick), and provincial and federal public health agencies.

The Society of Obstetricians and Gynaecologists of Canada

Lyme-Aid: Helping Pregnant Women and their Healthcare Providers Prevent Lyme Disease and other Tick-Borne Diseases During Pregnancy

Project Summary: The rising public health concern posed by climate driven zoonotic, food borne and water-borne infections, including Lyme disease and other tick-borne diseases, is significant. It is critical that Canadians have access to timely and accurate information to better understand their risks and take measures to prevent infection.

Women of reproductive age who are planning a pregnancy or who are pregnant may be at increased risk of infection and complications for their baby. Both women and their healthcare providers must be made aware of the most current and up-to-date evidence in order to take precautionary measures to prevent infection, to recognize signs and symptoms of infection and to understand treatment approaches that will mitigate risk and optimize outcomes for mothers and their babies.

The SOGC will review the current evidence on effects of Lyme disease and other tick-borne diseases on pregnancy and pregnancy outcomes, determine healthcare providers' current knowledge and practices related to prevention and treatment, and create and disseminate resources for women and their healthcare providers with the aim of preventing exposure.

For more information please contact info@sogc.com.

Conseil des Abénakis de Wôlinak
Led by Mr. Jérémy Demers-Poliquin

Lyme disease research and monitoring in Abénakis de Wôlinak territory

Project summary: With the support of the Public Health Agency of Canada, the Abenaki Council of Wôlinak is currently working on a project to determine whether or not Lyme disease is present in the territory of the Abenaki Nation. This territory includes two Indigenous communities, the communities of Wôlinak and Odanak.

To verify the presence of Lyme disease in the territory, the Abenaki Council of Wôlinak are conducting inventories of black-legged ticks (*Ixodes scapularis*), given that they are the main factor of this disease. Two types of sampling are done in the context of this study.

On the one hand, the Abenaki Council of Wôlinak proceeded with black-legged tick inventories directly in the territory of the Wôlinak community in summer 2018. For this purpose, several parcels of land presenting ideal habitat conditions for the ticks were surveyed in transects. The method used to capture the ticks was the flannel flag-dragging protocol established by Professor Virginie Millien's research team of McGill University.

The Abenaki Council of Wôlinak are also collecting ticks on white-tailed deer carcasses at wildlife registration stations in the Centre-du-Québec region, more specifically at Baie-du-Febvre, Drummondville, Plessisville and Victoriaville. This inventory is being conducted in fall 2018 and the protocol used in fact is an adaptation of the Quebec winter tick monitoring protocol of the Ministère des Forêts, de la Faune et des Parcs du Québec.

All the black-legged ticks collected during these two types of sampling campaigns are sent for analysis to Canada's National Microbiology Laboratory to find out the degree of contagion of the ticks with *Borrelia burgdorferi* bacteria, responsible for Lyme disease. In addition to feeding the database associated with the progression of Lyme disease in Quebec, this project will make it possible to know the areas most at risk for the two Indigenous communities (Wôlinak and Odanak) and for the Centre-du-Québec region.

Finally, the project includes a Lyme disease awareness component. Residents of the two Indigenous communities, both children and adults, are made aware through informative documents and activities. The Abenaki Council of Wôlinak are also paying special attention to Wôlinak and Odanak hunters, who have been invited to participate in the project by examining their white-tailed deer carcasses. The non-Indigenous hunters the Abenaki Council of Wôlinak meets at the wildlife registration stations are also informed.

For more information, please contact Jérémy Demers-Poliquin by email at jdpoliquin@cawolinak.com, or by telephone at (819) 294-6696, extension 2501.

Conseil de la Nation Huronne-Wendat

Surveillance activities and raising awareness among the Huron-Wendat Nation regarding Lyme disease risk and prevention

Project summary: The Huron-Wendat Nation Council created the Office of the Nionwentsïo in 2018. Its roles include protecting and maintaining the quality of the territory, and preserving the traditional activities of the Huron-Wendat Nation.

The purpose of this pilot project is to determine the risk factors affecting the likelihood of Huron-Wendat Nation members contracting Lyme disease while carrying out various activities on their traditional territory of Nionwentsïo (e.g., hunting deer or moose in a mixed habitat). Lyme disease is caused by the bacterium *Borrelia burgdorferi*. These bacteria are transmitted through the bite of infected *Ixodes scapularis* ticks.

The project also aims to raise awareness among the Huron-Wendat Nation Council's biological team and to train them on how to perform ticking monitoring activities. The project will be carried out in close collaboration with the Institut national de la santé publique du Québec (INSPQ), which worked with the University of Montréal to develop standardized field collection techniques.

The biological inventories collected by Huron-Wendat Nation Council employees will:

1. enable the Huron-Wendat Nation Council to collect data on *I. scapularis* ticks independently;
2. generate new data for Quebec's integrated Lyme disease monitoring program; and
3. lead to new findings by having a collection of *I. scapularis* ticks in Quebec.

The data collected will be added to the provincial monitoring data to track the spread of Lyme disease, improve Lyme disease risk maps and identify endemic areas. Finally, information sessions with Huron-Wendat Nation members and employees will be offered, along with a leaflet designed specifically for Huron-Wendat Nation members and non-Native hunters. This will help these groups be more aware of how they can protect themselves from *I. scapularis* and Lyme disease.

For more information, please contact Amélie D'Astous by email at amelie.dastous@cnhw.qc.ca.

Government of Newfoundland and Labrador

***Determining the Environmental Burden of Lyme Disease
in Newfoundland and Labrador***

Project summary: The one-year project, which will begin in April 2019, includes passive, active and sentinel surveillance:

- Passive surveillance will involve asking island residents to submit ticks to the Animal Health division, for species identification and analysis for the presence of *B. burgdorferi*.
- Active surveillance will involve active tick dragging in regions where ticks have been found and will increasingly be found as a result of climate change.
- Sentinel surveillance will involve taking blood samples from dogs to test for previous exposure to *B. burgdorferi*.

Please contact Douglas Howse (douglashowse@gov.nl.ca or (709) 729-3422) for more information.

National Lyme disease research networks

New Canadian Lyme Disease Research Network (CLyDRN)

Vision: The Canadian Lyme Disease Research Network (CLyDRN), based at Queen's University will conduct multidisciplinary research on tick-borne illnesses, with a focus on Lyme disease. The goal of the research group is to promote excellence in regards to the following pillars:

1. Research and diagnosis related to epidemiology, entomology, pathogenesis and laboratory medicine to minimize the impact of tick-borne illnesses on Canadians
2. Surveillance methods, through both active and passive measures, so as to enhance prevention and control of Lyme disease and other tick-borne illnesses
3. Communication, through education, engagement and awareness of the prevalence of tick populations in specific areas, as well as the associated risk

Mission: The vision will be accomplished through a multi-centric, collaborative and team-based approach. The research group would make use of existing resources, and expertise from various groups including: the National Microbiology Laboratory, Public Health Ontario, the Public Health Agency of Canada, the British Columbia Centre for Disease Control, Nova Scotia Health and Wellness, and Queen's University. Together we have over 40 research partner agencies from across Canada with 90 key members including community and patient advisors.

Values:

- **Innovation & Excellence:** The Research Network would be the first group of its kind at a Canadian university and would promote new and meaningful research.
- **Collaboration:** The goal of the research group would be to bring experts from various disciplines together, including patients, clinicians, microbiologists, mathematicians, biologists, and public health professionals, to form a multidisciplinary team with a common interest in Lyme disease.
- **Relevance:** The research group would explore areas significant to Canadians and their needs, given that Lyme Disease is becoming an increasingly pressing issue.

Impact: The Canadian Lyme Disease Research Network will facilitate an increase in our understanding of LD by promoting collaboration and knowledge translation between research groups with access to state of the art infrastructure and resources. The concentration of this expertise will generate new strategies to curb this microbial threat in Canada, and aligns well with recent Federal and Provincial efforts to mobilize resources to tackle this growing problem.

Consequently, the group would hope to improve the awareness of LD by the public and by healthcare providers, enhance national surveillance to pinpoint where the disease is emerging and which populations are at risk, and lastly, gain new insights into effective diagnosis; currently a major gap in our knowledge of Lyme Disease.

For more information on this research network, please visit the website at: <https://www.clydrn.ca/>. You can also contact Dr. Kieran Moore by email at kieran.moore@kflaph.ca.

Canadian Lyme Consortium (CLC)

The Canadian Lyme Consortium was established to blaze a fresh trail in multidisciplinary, patient-centered investigation into Lyme and associated diseases.

This research network combines innovative science and technology with unique models of stakeholder engagement to address the substantial gaps that exist in the understanding, diagnosis, and treatment of complex, debilitating illness. It provides a unique platform for collaboration, consultation, multi-sector engagement, and knowledge exchange. CLC membership includes researchers, clinicians, and representatives of the patient and advocacy communities who collectively shape the vision of this network.

CLC currently benefits from research nodes in the Maritimes (Mount Allison Lyme Research Network), Quebec (Laval / IBIS), Ontario (G. Magnotta Lyme Disease Research Lab at the University of Guelph), and Alberta (Tick Microbiome Initiative, University of Alberta), as well as international collaborators. All members share the common goal of working with and for the patient community to advance knowledge, and reduce the burden of Lyme disease within and beyond this country.

For more information, please see [www. www.clymec.ca](http://www.clymec.ca) or email Melanie Wills (mwills@uoguelph.ca).

Other information as shared by participants

Collective Lyme Patient Group Statement in response to the Minister's Award of \$4 million for a Lyme disease research network

Lyme patient groups from across Canada are unified in their concern over the federal Minister of Health's awarding of \$4 million of Canadian taxpayer monies for Lyme disease research to a research group that has not included the patient voice in a meaningful and inclusive way from its initial conception and on up through all stages of research development.

We strongly agree with the CMAJ's deputy editor, Kirsten Patrick, who wrote in the October 16, 2016 issue of the CMAJ:

*'For each step in the research process, investigators need to consider how best to involve patients in planning and decisions. For patient-relevant research to be meaningful, patient and public engagement in research cannot comprise a token lay person on a research ethics review board. Patients and their caregivers must be involved in decision-making at all steps in the research process, from design to choice of primary and secondary outcomes, through dissemination and implementation.'*¹

A robust and fully inclusive patient voice is of utmost importance in Lyme disease research for true advances in testing, diagnosis and treatment to come about.

Patient groups feel that at least two Lyme disease research networks are necessary in Canada to ensure differing viewpoints are heard. The status quo has not served Canadians well up-to-this-point. Differing opinions need to be heard, understood and embraced before we can effectively move this issue forward. Independent researchers can also make an impact and we need to ensure that they are also heard. While Lyme patient groups support thousands of Canadians who are now living with tick-borne illnesses, we also work hard to prevent even more Canadians from experiencing tick-borne illnesses down-the-road. It's time for real change and that can only come about with meaningful patient engagement!

¹<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5056863/>

Signed By: Canadian Lyme Disease Foundation, L'Association québécoise de la maladie de Lyme, Lyme Disease Association of Alberta, Lyme Disease Association of B.C., LymeHope, Lyme Ontario, Manitoba Lyme and Tick-borne Diseases, New Brunswick Lyme Disease Association Inc. – LymeNB, Nova Scotia Lyme Disease Support Group, Ontario Lyme Alliance, Saskatchewan Lyme Disease Association, VOCAL Ottawa

Open letter to PHAC

2018 11 02

Ms. Kimberly Elmslie
Vice-President
Infectious Disease Prevention and Control Branch
Public Health Agency of Canada

Mr. Steven Sternthal
Director General
Public Health Agency of Canada

Dear Ms. Elmslie and Mr. Sternthal:

Thank you for the invitation to attend the October 24th Lyme Disease Multi-disciplinary WebEx Roundtable. We have some additional comments and reflections that we would like to share with you and we trust that this letter will also be shared with all the stakeholders in your follow-up communications regarding this meeting. We wish to emphasize that we value meaningful engagement and hope that these comments will facilitate that outcome.

We would like to point out what might not be immediately evident, but members of the patient, advocacy, medical and research communities volunteer their time in order to attend these meetings. This means for some, they must take time off from work – often as vacation time or unpaid leave. Clinicians have to reschedule patients, which impacts those patients, as well. This means that there are costs incurred for community members which are not similarly experienced by those whose attendance is part of their work, so it follows suit that the expectation of benefit is set higher for community members and our comments reflect this consideration.

First, while we recognize that PHACs mandate emphasizes prevention, prevention was not one of the issues the stakeholders identified as the agreed upon top four priorities at the June 19th Lyme Disease Multi-disciplinary Roundtable meeting. So, while the children's tick exhibit introduced at last week's meeting has merit down-the-road, it was unfortunate that this exhibit was highlighted in the agenda when so many other far more urgent issues that are impacting human care were not even touched upon.

One of the most critical issues is treatment. At the June meeting, a recommendation was made by several stakeholders that a chart of the 2014 ILADS Lyme Disease Treatment Guidelines be posted on the PHAC Healthcare Providers webpage similar to the chart that is posted for the 2006 IDSA Lyme Disease Treatment Guidelines. We understood, as did many others at the June meeting, that there was agreement that this suggestion would be acted upon by PHAC. However, to date the webpage has not been revised. Could we please be given a concrete date as to when these changes to the website will be posted? Both physicians and patients need to be fully aware that there are two sets of treatment guidelines for Lyme disease. This is one way that PHAC could take action to better manage human cases of Lyme disease.

A suggestion was made in the WebEx chatroom that the recently published work quantifying the under-detection of Lyme disease in Canada be shared with the stakeholders. Since it was not, we feel it is important that all members of the stakeholder group be made aware of this critical new piece of research that has a profound effect on pretest probability which is critical in interpreting diagnostics. This paper is found at <https://www.mdpi.com/2227-9032/6/4/125>

At the June meeting it was recommended that there be changes made to the wording on test results sent to physicians to specifically identify that the use early serology is not appropriate, a clinical diagnosis is needed. Further, that a negative test result does not rule out Lyme disease and also that physicians be informed that they can obtain reporting on individual Western Blot bands. Has there been any progress made to set up a committee to address this? If not, when will this be acted upon and will the critically important call for representation by knowledgeable patient representatives be honoured?

We also would like to make suggestions of structural changes that could improve communications for future meetings:

1. It is important that patients and their representatives have input into the agenda as it is being drafted and there should be a reasonable attempt to include agenda items they would like to address.
2. To help individuals decide if a meeting would warrant the investment of their time, it would be appropriate to present the agenda along with the meeting invitation.
3. It would be useful to submit at least some summary material in advance so it could be translated and shared as a pre-meeting preparation tool. Translation in both official languages, of at least a summary of the material being covered, needs to be provided to all participants during the meetings so that what is being presented and discussed is fully understood.

Finally, it is important to recognize that there are, and have been for many years, two Canada-wide research networks working on Lyme disease/tick-borne diseases. While the Canadian Lyme Disease Research Network (CLyDRN) primarily has a public health focus, the Canadian Lyme Consortium (CLC) is patient-supported. Declining to make reference to the CLC as one of Canada's two Lyme disease research networks indicates a bias for one network over the other. This is inappropriate and is seen by Canadians to exhibit a lack of integrity at the highest levels of Canada's public health system. It is our hope that PHAC will help achieve a balance of ideologies by acknowledging that there are two national research organizations in existence and that the work being done by the CLyDRN and the CLC are given equal importance in future PHAC meetings and updates.

We are happy to answer any questions and look forward to your response.

Sincerely,

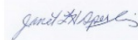
Vett Lloyd, PhD, Mount Allison University

Linda Kelso, Co-Founder, Ontario Lyme Alliance

Janet Sperling, CanLyme

Sue Faber, Co-Founder LymeHope

Liz Zubek, M.D.



Lyme Disease – Five Immediate Patient Needs

The following five pillars for diagnosing and treating Lyme disease are currently the basic needs of Lyme disease patients across Canada:

1. One ILADS-trained physician/naturopathic physician is needed in every health unit area/Lyme disease risk area across Canada. Physician training is available through the ILADS Physician Training Program. The contact person is Ms. Barbara Buchman. Her e-mail is barbarabuchman@ilads.org.
2. TESTING: Rather than using the provincially-funded, two-tier Lyme disease test, the Lyme immunoblot test (ie. ImmunoBlot by IGeneX) should be considered. It tests for both U.S. and European strains of Lyme *Borrelia*. The sensitivity of this test is greater than 93.0% compared with the two-tiered system that has a sensitivity of only 48.6%. Western blot testing that includes the species-specific protein bands 31 kDa (OspA) and 34 kDa (OspB) should also be included. All protein bands present must be reported to the health-care provider. Also, an interpretation of the protein bands should be included with the report explaining their significance. For example: a) species-specific bands for the Lyme disease bacterium, *Borrelia burgdorferi* (i.e., 18, 23-25, 30, 31, 34, 37, 39, 58, 83, 93), b) *Borrelia*-specific bands (i.e., 41) and/or, c) non-specific bands (i.e., 45, 66).

A nucleic acid amplification test, (eg., Nanotrap) can identify specific pathogen DNA. Not only does this method measure the presence of the Lyme disease bacterium, it reveals active infection.

Shortly after a tick bite, patients should consider antigen detection screening, such as the Lyme Antigen Test that uses direct detection of *Borrelia burgdorferi* protein in the urine. If using an immunoblot test, patients must wait 4–6 weeks for the body to produce sufficient levels of antibodies to seroconvert.

Federal legislation is needed, which states that anyone who tests negative on Lyme disease tests, must be informed that they can still have Lyme disease. Lyme disease is a clinical diagnosis.

3. Health-care providers must accept test results for tick-borne diseases conducted by CLIA-approved laboratories in the U.S.A. and Europe.
4. The licensing colleges must get off the backs of physicians who treat Lyme disease using the 2014 ILADS guidelines. The IDSA guidelines have been delisted from the U.S.A. National Guideline Clearinghouse, and no longer exist. Also, the Case Definition for Lyme disease needs to be re-written.

5. Naturopathic physicians, who have in-service training and certification for using antimicrobials (oral and I.V.), must be allowed to prescribe them, when clinically necessary.

John D. Scott, B. Sc. (Agr.), M. Sc.
Lyme Disease Research Scientist
ILADS member and presenter (2011 & 2018)
jkscott@bserv.com

November 2, 2018

Other links and references

The Canadian Veterinary Medical Association would like to reiterate the importance of a one health approach as we collectively engage in managing insect vector-associated health challenges in Canada. Domestic animals should be included in epidemiologic surveys owing to the fact that cattle and other ruminants as well as equids spend time on pasture. A Lyme disease vaccine is at least available for dogs and is used safely off-label in horses.

National tick awareness month:

<https://www.canadianveterinarians.net/practice-economics/practice-tools-national-tick-awareness-month>

ZOETIS marketing campaign – ‘Lonestar Louie’:

<http://www.newtickintown.ca/>

Pet Tick Tracker program:

<https://www.wormsandgermsblog.com/2017/05/articles/animals/dogs/petticktracker-update/>

Publications:

- Canadian Medical Association Journal (CMAJ), November 7, 2018; volume 190, Issue Supplement which includes several articles that may be of interest on engaging patients in health research:
<http://www.cmaj.ca/content/190/supplement>
- A systematic review on the impact of gestational Lyme disease in humans on the fetus and newborn:
<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0207067>
- Under-Detection of Lyme Disease in Canada:
<https://www.mdpi.com/2227-9032/6/4/125>
- Human Babesiosis caused by *Babesia duncani* has widespread distribution across Canada:
<https://www.mdpi.com/2227-9032/6/2/49>
- Design and Implementation of N-of-1 Trials: A User’s Guide: <https://effectivehealthcare.ahrq.gov/topics/n-1-trials/research-2014-5>

WebEx Follow-up: Questions and Answers

The following two questions were received but due to time constraints, were unanswered during the WebEx meeting.

Q. One of the pillars identified by patients, and one of the main topics identified as a priority in the meeting last June, was treatment. Are there any updates (concrete date) on when the Public Health Agency of Canada (PHAC) will put the International Lyme and Associated Diseases Society (ILADS) treatment recommendations on the webpage for healthcare providers/side by side with the currently posted Infectious Disease Society of America (IDSA) guidelines? (Proposed action item from June Roundtable)

A. PHAC has not added information to the website comparing existing guidelines on Lyme disease. This is because we are currently reviewing the web content to confirm what will be posted and the criteria upon which we will include information that has not been developed by PHAC.

Q. In keeping with the discussion and information/updates being provided on Lyme disease projects, can we discuss Dr. Vett Lloyd and Dr. Ralph Hawkins' paper on the under detection of Lyme disease in Canada?

A. Link to the report “Under-Detection of Lyme Disease in Canada” was shared in the comment section on the WebEx, and is also being shared as part of the follow-up package.

Public health surveillance is the foundation of effective public health practice. This allows us to identify where the risk is and the population groups to which additional prevention efforts should be directed.

Cases of Lyme disease are reported to PHAC by provincial and territorial public health organizations, which allow PHAC to provide surveillance data at the national level. In 2017, provincial and territorial public health organizations reported 2025 cases of Lyme disease. However, this number does not reflect every case of Lyme disease that is diagnosed in Canada every year.

PHAC recognizes that a degree of under-reporting of cases is present in all disease surveillance systems, and the precise rate of under-reporting is usually not known.

PHAC will continue to work to enhance its current surveillance program for both ticks and human cases, in partnership with provincial partners. These partnerships are essential to collect information and data, and support organizations to mitigate the risk by implementing evidence-based public health interventions and practices.

Annex A: Agenda

Public Health Agency of Canada

Multidisciplinary Roundtable Discussion on Lyme Disease

Follow-up WebEx Meeting

AGENDA

Wednesday, October 24, 2018

1:00 pm to 3:00 pm EST

MEETING OBJECTIVES:

- Review the proposed action items from the June 19, 2018, Roundtable held in Ottawa.
- Confirm organizational interest and leads for the proposed action items.
- Identify status of organizational efforts and initiatives related to the proposed action items.
- Support information sharing and collaboration amongst Lyme disease stakeholders.

13:00 – 13:05	Welcoming Remarks and Review of Meeting Objectives	Kim Elmslie
13:05 – 13:10	Participant Roll Call	All
13:10 – 13:30	Engagement of Indigenous Populations <ul style="list-style-type: none">• Review proposed action items.• Confirm organizational interest and leads.• Status on the proposed action items.	All
13:30 – 13:50	Diagnosis <ul style="list-style-type: none">• Review proposed action items.• Confirm organizational interest and leads.• Status on the proposed action items.	All

13:50 – 14:10	Maternal-Child Transmission <ul style="list-style-type: none"> • Review proposed action items. • Confirm organizational interest and leads. • Status on the proposed action items. 	All
14:10 – 14:30	Treatment <ul style="list-style-type: none"> • Review proposed action items. • Confirm organizational interest and leads. • Status on the proposed action items. 	All
14:30 – 14:35	Other PHAC Updates <ul style="list-style-type: none"> • PHAC and Ingenium Canada – new interactive exhibit on ticks for children (pilot) 	Communications and Public Affairs Branch (TBC)
14:35 – 14:55	Participant’s Perspective <ul style="list-style-type: none"> • Are there any other participant-led initiatives related to Lyme disease that anyone would like to share? 	All
14:55 – 15:00	Adjournment <ul style="list-style-type: none"> • 2019 Multidisciplinary Roundtable on Lyme Disease 	Kim Elmslie



Annex B: List of Participants

ORGANIZATION	PARTICIPANT
FEDERAL GOVERNMENT	
Public Health Agency of Canada	Kim Elmslie Steven Sternthal Lesley Doering Lindsay Colas
Canadian Institutes of Health Research	Kelly Taylor
Health Canada – Communications Branch	Josiane Lacelle
PROVINCIAL GOVERNMENT	
Ontario Ministry of Health and Long-Term Care	Nina Arron
Institut national de santé publique du Québec	Dr. Karine Thivierge
Manitoba Health	Scott Graham-Derham on behalf of Dr. Richard Rusk
Government of Newfoundland and Labrador	Douglas Howse Claudia Sarbu
New Brunswick Department of Health	Dr. Jackie Badcock
Nova Scotia Department of Health and Wellness	
Saskatchewan Ministry of Health	Dr. Denise Werker
HEALTH PROFESSIONALS AND ORGANIZATIONS	
Association of Medical Microbiology and Infectious Disease Canada	Dr. Dan Gregson Dr. Todd Hachette
Canadian Association of Naturopathic Doctors	Shawn O'Reilly
Canadian Association of Schools of Nursing	Janet Nevala Kristine Crosby
Centre for Effective Practice	Lena Salach Matthew Gray
Family Physician	Dr. Elizabeth Zubek
The Society of Obstetricians and Gynecologists of Canada	Dr. Courtney Green Jocelynn Cook Kyla Kaminsky
Registered Nurses' Association of Ontario	Sue Faber
Canadian Veterinary Medical Association	Dr. Marilyn Keaney Dr. Shane Renwick
College of Family Physicians of Canada	Dr. Marg Sanborn
Kingston, Frontenac, Lennox & Addington Health Unit	Liam Remillard

ORGANIZATION	PARTICIPANT
PATIENT GROUPS	
Association québécoise de la maladie de Lyme	Robert Hunneault Annie Roussy
Lyme Disease Association of Alberta	Colin Davison
LymeNB	Janet Higgins
Lyme Ontario	Ellen Hohs
Manitoba Lyme Disease	Marnie Lepage
Nova Scotia Lyme Disease Support Group	Donna Lugar
Ontario Lyme Alliance	Linda Kelso
Saskatchewan Lyme Disease Association	Triant Steuart
CanLyme	Jim Wilson Janet Sperling
Voices of Canadians About Lyme (VOCAL)	Kristy Giles
ACADEMIA / RESEARCH	
G. Magnotta Foundation	Dr. Felix Sperling
Mount Alison University	Dr. Vett Lloyd
G. Magnotta Lyme Disease Research Lab (University of Guelph)	Dr. Melanie Wills
Bishop's University	Jade Savage Pierre Chuard
University of Toronto	Dr. Samir Patel Beate Sander
OTHER ORGANIZATIONS	
Conseil des Abénakis de Wôlinak	Jérémi Demers Poliquin
Conseil de la nation Huronne-Wendat	Philippe Berthiaume