Combatting Lyme Disease Through Collaborative Action

Ontario’s 10-Step Education and Awareness Plan

July 2016
Ministry of Health and Long-Term Care
Copies of this report can be obtained from
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Combatting Lyme Through Collaborative Action
Ontario’s 10-Step Education and Awareness Plan
Message from the Minister of Health and Long-Term Care

Combatting Lyme Disease Through Collaborative Action: Ontario’s 10 Step Education and Awareness Plan is the first step in the Ontario government’s efforts to protect the people of Ontario from Lyme disease.

The Ontario government has been working with its partners in public health and with other stakeholders to make sure that Ontarians and the health care providers they rely on have the information they need about Lyme disease. Ontario is also working to ensure patients have access to the best evidenced-based care options we can provide.

Whether you live in a high-risk area or may be travelling to one all Ontarians need to be aware of Lyme disease. As part of Ontario’s Patients First: Action Plan for Health Care we made a commitment to the people of Ontario to provide the education and information they need to make the right decisions about their health.

Our 10-Step Education and Awareness Plan on Lyme disease will provide you with the information you need about Lyme disease and outline the steps our government is taking to protect Ontarians from the disease.

Together with all of our partners Ontario remains committed to putting people and patients first as we strive to meet the challenge of Lyme disease.

Dr. Eric Hoskins
Minister
Health and Long-Term Care
About this 10-Step Education and Awareness Plan

Every spring, Ontarians head outside to explore all the natural beauty that our province has to offer. Recreational activities such as camping, fishing, hiking, golfing and hunting make our province second to none in providing the perfect backdrop for keeping fit and healthy while enjoying the fresh air and natural surroundings.

Whether taking part in recreational activities, working outdoors, living in rural areas or travelling abroad Ontarians are encouraged to include the prevention of tick bites that can lead to Lyme disease in their plans. Lyme disease is a public health concern that exists not only in Ontario but also across North America, Europe and Asia.

Lyme disease threatens the health of Ontario residents – last year there were approximately 400 reported cases in Ontario. The symptoms of Lyme disease may appear minor at first. However, if left untreated, Lyme disease can have a devastating impact on individuals, families and communities.

The Ontario Lyme Disease Education and Awareness Plan focuses on protecting us all from Lyme disease. At its core, this Plan is a roadmap for improving awareness, education, prevention and control of Lyme disease in Ontario.

This Plan builds on the efforts of the many agencies, communities and individuals who are already doing so much in the field of Lyme disease and advocating on behalf of patients.
Our 10-Step Education and Awareness Plan Supports Patients First

This Plan supports Patients First: Action Plan for Health Care, Ontario’s plan for changing and improving its health system. Patients First exemplifies our commitment to put people and patients at the centre of this strategy by focusing on four pillars:

ACCESS

1. Improve the availability of the information, tools and supports people need—when and how they need them
2. Strengthen intergovernmental co-ordination of Lyme disease initiatives and prevention
3. Support the availability of consistent signage and information at all provincial parks in risk areas

CONNECT

4. Engage a broad range of voluntary and non-governmental groups/organizations
5. Facilitate effective patient-health care provider interactions about care, treatment and support options available

INFORM

6. Launch a comprehensive, province-wide awareness and education campaign
7. Expand health care provider education to strengthen the focus on care, treatment and support

PROTECT

8. Increase awareness of Lyme disease risk areas and the possibility of infected ticks being found outside known risk areas
10. Contribute to the development of an Ontario Lyme research agenda
Taking Stock: Lyme Disease in Ontario

What is Lyme Disease?

In Ontario, Lyme disease is caused by *Borrelia burgdorferi* bacteria. In other jurisdictions, different species and strains of Borrelia bacteria have been known to cause Lyme disease. In Ontario, this bacterium is passed to humans through the bite of infected blacklegged ticks which are also known as deer ticks.

The transmission of the bacteria from an infected tick to a human is thought to usually take at least 24 hours. Early in their life cycle, ticks are as small as the period at the end of this sentence. At the nymph stage, when they are most likely to infect humans and animals, they can be as small as the size of the head of a pin— and it is this small size that makes them easy to overlook on the body (see image 1). A bite may occur without being noticed. The most effective way to prevent Lyme disease is to prevent tick bites.

![Image 1: Ticks at different stages of life cycle](Photo courtesy of the Public Health Agency of Canada)
Symptoms

The most commonly known symptom of Lyme disease is the appearance of an expanding, mildly-itchy to non-itchy rash (called an ‘erythema migrans’ rash). The rash begins at the site of the tick bite between three to 30 days after exposure and usually grows in size for several days before it begins to fade and eventually disappears. It is important to know however, that not everyone gets a rash and that even if they do a person may not notice one if it is on a hard-to-see part of the body. If there is a rash it’s advisable to take (and date) photos with a tape measure beside the rash to determine the size.

Flu-like symptoms, fatigue, fever, headaches, swollen glands as well as muscle and joint pain are a few of the most common early signs of Lyme disease. If the disease is left untreated many other symptoms may also develop in the weeks to months following exposure. These symptoms could potentially last for years and may include: additional rashes, joint pain and swelling, neurological problems, shooting pains, numbness and tingling, balance and/or memory difficulties, dizziness and heart palpitations, severe headaches, loss of muscle tone in the face (resembling Bell’s palsy) and paralysis, among others. Although uncommon, deaths from Lyme disease have been reported.

Note 1: Protecting Yourself from Tick Bites

In Ontario, black legged ticks that carry Lyme disease live in woodlands, tall grasses and bushes. If you spend time in these areas and an infected tick bites you it may pass the disease on to you. Protect yourself in the following ways:

- Wear light-coloured clothing. It makes ticks easier to spot.
- Wear closed toe footwear and socks, a long sleeved shirt and long pants. Tuck your shirt into your pants and your pants into your socks.
- Use a tick repellent that has DEET or Icaridin on clothes and exposed skin (be sure to follow the manufacturer’s directions).
- Search your clothes and body for ticks at least once a day, paying special attention to areas such as the groin, armpits, scalp, navel, behind the ears and knees. Use a mirror to check the back of your body or have someone else check for you.
- Take a shower as soon as you can after being outdoors to more easily find and wash off any ticks crawling on you.
- Before washing, place outdoor clothing through the dryer cycle for 60 minutes on high heat to kill any ticks that may be hard to see.
Testing, Diagnosis and Treatment

See a health care provider as soon as possible if you have symptoms or if you feel unwell in the weeks following a known bite or a possible (but unseen) bite. Be sure to tell them about your tick bite or possible exposure to ticks. If you saved the tick that bit you, bring it with you to your medical appointment for possible examination. Your health care provider may send the tick to the Public Health Ontario Laboratory for identification and testing as a part of the surveillance program in Ontario. Testing the tick can take weeks to complete, therefore, health care providers should not wait for tick test results to direct treatment decisions.

When testing is appropriate, patients are first tested using an enzyme-linked immunosorbent assay (ELISA) to detect antibodies against *B. burgdorferi*—the bacteria that can lead to Lyme disease. If results from the ELISA are positive or indeterminate, second tier testing using Western immunoblot assays (WB) is performed. Since antibodies can take time to develop, testing is not always accurate. International research into improved testing methods is ongoing. As such, primary care providers are encouraged to determine treatment options based on their clinical diagnosis and judgment, even in the absence of testing confirmation.

Lyme disease always needs to be a clinical diagnosis that should be based on patient history, which includes symptoms and exposure to the tick vector and physical findings. The presence of an erythema migrans rash is sufficient to diagnose Lyme disease and begin treatment. A history of a tick bite is not required. Patients suspected of having Lyme disease (known tick exposure and appropriate symptoms) should also begin treatment even in the absence of a rash.

When Lyme disease is diagnosed, antibiotics are prescribed for treatment. When administered early, an antibiotic regimen can usually effectively treat Lyme disease. Even after standard treatment however, some patients may continue to have symptoms of Lyme disease. This is more common in patients whose diagnoses were made further along in the course of the infection. There could be a number of possible reasons for lingering symptoms in individuals. The exact cause is not yet known and more research is needed to better understand these persistent symptoms.
Where Am I at Risk?

In Ontario, blacklegged ticks are most commonly found in areas along the north shores of Lake Erie, Lake Ontario and the St. Lawrence River. Locations with established blacklegged tick populations infected with Lyme disease include: Long Point Provincial Park, Turkey Point Provincial Park, Rondeau Provincial Park, Pinery Provincial Park, Rouge Valley, Point Pelee National Park, Prince Edward Point National Wildlife Area, Wainfleet Bog Conservation Area and the Thousand Islands National Park area. The Rainy River area of northern Ontario is also a risk area for Lyme disease.

It is important to note that infected ticks may occasionally be found in Ontario outside known risk areas. Multiple factors, including climate change, warmer winter temperatures and their ability to "hitch-hike" on suitable hosts (e.g., birds, deer) allow ticks to survive and to establish populations in new areas throughout the province. Despite ongoing surveillance, the potential for infection outside of established risk areas does exist. Furthermore, there are other species and strains of Borrelia bacteria that are known to cause Lyme disease found in other places around the world, so it is important to take precautions and protect yourself, whenever and wherever you might be at risk.

Public Health Ontario produces a map of estimated Lyme disease risk areas in Ontario, which is updated annually to include new areas as they are identified. The current map of Lyme disease risk areas is available at [Ontario Lyme Disease Map 2016: Estimated Risk Areas](#).

**Note 2: Protect Your Pets**

<table>
<thead>
<tr>
<th>If you have pets:</th>
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<tr>
<td>• Discuss appropriate tick control methods for your pet with a veterinarian.</td>
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<tr>
<td>• Regularly check pets that spend time outdoors for ticks (ticks may attach to pets, be carried indoors and then drop onto carpets, flooring or furniture and reattach to people in the household).</td>
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Removing a Tick — in 4 Easy Steps

Removing a tick is the same for humans and animals:

1. If the tick is attached to you use fine-tipped tweezers or a tick removal tool to grasp the head of the tick (not the body) as close to the skin as possible. When using a tool, use the tool to lift the tick out, DO NOT twist or spin the tick. Never use your fingers to remove a tick (see image 2).

2. Pull the tick straight out, gently but firmly, ensuring that the entire tick (including the head) is removed. Don’t squeeze it. Squeezing the tick can cause Lyme bacteria to be accidentally introduced into your body (see image 2).

3. After removing the tick, place it in screw-top bottle (like a pill bottle), and take it to your health care provider or local health unit. They may send it to the Ontario Public Health Laboratory for species identification and testing as part of the surveillance program. In Ontario, although only blacklegged ticks transmit Lyme disease, other types of ticks can cause other diseases.

4. Thoroughly cleanse the site of the bite with rubbing alcohol and/or soap and water.

Note!

- Do not burn the tick or use nail polish, petroleum jelly or another substance on the tick to try to make it pull away from your skin. These methods may cause Lyme bacteria to be injected into the skin.
- Remember and write down where you most likely acquired the tick. It will help public health workers to identify areas of higher risk.
- Treatment decisions should be made based on the tick type and risk of disease based on local epidemiology.
10-Step Education and Awareness Plan for Lyme Disease

ACCESS

1. Improve the availability of the information, tools and supports people need—when and how they need them

*Key activities will include:*

**A Lyme Disease Website:** The Ontario.ca/Lyme website will be updated in the summer of 2016. This site will provide scientific evidence-based, accurate and timely information about Lyme disease prevention and links to some information on diagnosis and treatment.

**A Lyme Disease Toolkit:** Lyme disease resources (e.g., a checklist of questions to ask your health care provider) will be made available on the ministry’s website.

**A Lyme Disease Case Management Tool:** Working with public health units, Public Health Ontario and the Public Health Agency of Canada, a Lyme disease case management tool has been developed. Administered by phone or in-person, public health units will use this tool to: identify the location of Lyme disease exposure in Ontario; assist in case and contact management; provide case counseling; assist with disease management; and obtain required data.

2. Strengthen intergovernmental co-ordination of Lyme disease initiatives and prevention

*Key activities will include:*

**Building on partnerships:** Working together with the federal and local levels of government, health care professionals, researchers and community organizations, we will explore new ways to leverage existing Lyme disease resources and best practices to address both public and health care provider concerns about Lyme disease. This will help to better inform Ontarians about Lyme disease prevention, diagnosis and treatment.
Sharing resources: We will supply health care providers with current information, tools and support through the development of new and revised health care provider continuing education materials developed by the Public Health Agency of Canada, Public Health Ontario and others. As the science and clinical management of this complex disease continues to evolve, knowledge gained from exchanges of information and strategies related to clinical and scientific research will be communicated to Ontario's health care providers. We are committed to ensuring that our health care providers have the information they need to provide the best available care, treatment and support to Ontarians.

Active participation in the national dialogue on Lyme disease: Ontario will play a lead role in shaping the development of the federal Lyme disease strategy through ongoing participation on the national Public Health Network Council's working group on vector-borne disease and other federal Lyme disease meetings and by promoting Ontario's Lyme Disease Education and Awareness Plan.

Implementing a public health unit Lyme disease working group: As part of its coordination and oversight role, the ministry will work with local public health units to provide common language, educational resources and other materials/tools to improve awareness across the province.

3. Support the availability of consistent signage and information at all provincial parks in risk areas

Key activities will include:

Signage: In conjunction with Ontario Parks, the Ontario Parks Association, the Ontario Trails Council and other outdoor organizations, the ministry will support a coordinated approach to communicating the risk of being exposed to Lyme disease in provincial parks within identified risk areas through consistent messaging for signage. The ministry will also coordinate with its federal partners to ensure that conservation areas and federal parks share this messaging.

Supporting stakeholders: By leveraging their extensive networks, we will assist stakeholder organizations in getting the appropriate information about prevention to all Ontarians who are visiting, working at, or living near the provincial parks or other at-risk areas.

Note 3: Early Successes

In June 2015, clinicians, academics, researchers and policy makers from across Canada met at the Best Brains Exchange one-day workshop to review the effectiveness of current Lyme disease testing and to identify areas for improvement, as the first step toward a national research agenda.
Note 4: Creating Public Awareness

Ontario’s public awareness campaign focuses on how to protect yourself, what to look for, and what to do if you, a friend or a loved one shows symptoms of Lyme disease. The campaign targets all Ontario residents but has an increased emphasis on communities in high-risk areas during peak tick season - from early spring through to the end of autumn.

CONNECT

4. Engage a broad range of voluntary and non-governmental groups/organizations

Key activities will include:

Working with the Lyme Disease Stakeholder Reference Group: The Lyme Disease Stakeholder Reference Group is made up of health care professionals, public health policy experts, provincial Lyme disease advocacy groups, outdoor organizations and, federal and local government representatives who meet regularly to identify opportunities to improve awareness, education, prevention, control and timely diagnosis and treatment of Lyme disease in Ontario. The ministry will undertake a review of the group’s mandate and membership to ensure that external participants continue to have an active role in helping to inform provincial policy for Lyme disease.

5. Facilitate effective patient-health care provider interactions about care, treatment and support options available

Key activities will include:

Convening a patient/health care provider roundtable: We will organize a roundtable with health care providers and those living with Lyme disease, their families and caregivers to discuss common goals surrounding treatment options and access to timely care and support.

Expanding our understanding of health care provider attitudes and opinions about Lyme disease: An anonymous online survey designed to identify overall awareness of Lyme disease in primary care providers has been conducted. The results of this public research will help us understand how to more effectively target educational campaigns.

Engaging with researchers and health care experts from other jurisdictions who have diverse perspectives: To ensure that Ontario is familiar with the most up-to-date scientific information available.
Note 5: Early Successes

The ministry’s Lyme Disease Stakeholder Reference Group includes representatives from:

- Association of Municipalities of Ontario
- Association of Medical Microbiology and Infectious Disease Canada
- Centre for Public Health and Zoonoses
- College of Nurses of Ontario
- College of Physicians and Surgeons of Ontario
- College of Veterinarians of Ontario
- Conservation Ontario
- Ducks Unlimited
- G. Magnotta Foundation for Vector-borne Disease
- Lyme Ontario
- Nature and Outdoor Tourism Ontario
- Ontario Association of Naturopathic Doctors
- Ontario Association of Veterinary Technicians
- Ontario Camps Association
- Ontario College of Family Physicians
- Ontario Federation of Agriculture
- Ontario Federation of Anglers and Hunters
- Ontario Homeopathic Association
- Ontario Lyme Alliance
- Ontario Medical Association
- Ontario Parks
- Ontario Parks Association
- Ontario Trails Council
- Ontario Veterinary Medical Association
- Public Health Agency of Canada
- Public Health Ontario
- Registered Nurses Association of Ontario
INFORM

6. Launch a comprehensive, province-wide awareness and education campaign

Key activities will include:

Informing and educating Ontarians: Working with external partners, the ministry is committed to increasing awareness about the prevalence and effects of Lyme disease in the province. Through marketing, social media, improved communications with provincial stakeholders and ongoing education, we will ensure that Ontarians are aware of the risks posed by Lyme disease and how to prevent it. 

Lyme disease workshops/education sessions geared to children and pet owners: The ministry will assist in developing information modules for schools, camps and veterinary clinics to improve awareness among children and pet owners, especially in high-risk areas. We will also explore how school boards can provide valuable assistance in communicating and distributing Lyme disease information through the education system.

Note 6: Educating Health Care Providers

In September 2015, over 400 people participated in a webcast hosted by Public Health Ontario, the Ontario Hospital Association and the ministry. First of a series, the aim of the webcast was to convey information about Lyme disease trends, diagnosis, testing and treatment options in Ontario.

The webcast was attended by: chiefs of staff, vice presidents of clinical services, chief nurse executives, vice presidents of programs and patient safety, medical affairs directors, physicians, clinicians, occupational health and safety administrators, infection control practitioners, public relations/communications staff, emergency preparedness leads, emergency response teams and risk managers.

7. Expand health care provider education to strengthen the focus on care, treatment and support

Key activities will include:

Sharing information bulletins for primary care providers: In collaboration with Public Health Ontario we will issue regular information bulletins to primary care providers. In conjunction with improved education and training, these bulletins will support primary-care providers to consider Lyme disease in their diagnoses and management.
Continuing medical education modules: The ministry will partner with reputable expert bodies such as provider associations and regulatory entities to develop continuing medical education modules. These modules will describe the agent, mode of transmission and prevalence of Lyme disease in Ontario; tips on providing guidance to patients on the prevention of Lyme disease and how to treat patients appropriately for Lyme disease; and, describe the clinical manifestations of acute and late-stage Lyme disease and indications for testing.

PROTECT

8. Increase awareness of Lyme disease risk areas and the possibility of infected ticks being found outside known risk areas

Key activities will include:

Updating provincial risk area map: Public Health Ontario has developed a provincial map of geographic areas known to have increased risk for Lyme disease. The map will continue to be updated every year and new risk areas will be added based on ongoing tick surveillance.

Increasing availability of local risk area information: Local public health units have access to more detailed information about local high-risk areas as a result of their ongoing surveillance. Their information will also identify risk areas on a much more defined level than the provincial map.

Developing a provincial Lyme disease tick surveillance strategy: Working directly with Public Health Ontario, local public health units in Ontario are taking the lead in developing and implementing a tick surveillance strategy to improve the monitoring and identification of Lyme disease risk areas in the province. In support of this activity Public Health Ontario will explore ways to improve or expand vector-borne disease surveillance reports to include more tick surveillance data.
Note 7: Conducting Surveillance

Ontario uses both passive and active tick surveillance activities to monitor the risk of acquiring Lyme disease across the province. Surveillance is used to determine risk levels in a specific geographic region, but does not directly influence treatment decisions.

**Passive** tick surveillance is based on examining ticks brought into health units or to health care providers by members of the public, and by human cases reporting the location of their most likely exposure to public health.

**Active** tick surveillance is based on public health professionals collecting ticks from their natural habitat by drag sampling. Drag sampling consists of dragging a white flannel cloth over and around vegetation where ticks may be present, and then collecting and examining the ticks found on the white flannel cloth. Drag sampling (also known as tick-dragging) is usually done in the spring and fall, when adult ticks are most prevalent. Active surveillance is not undertaken on private lands or in remote areas.


*Key activities will include:*

**Providing updated** evidence-based information on scientific technical issues, for example, on the use of both passive and active surveillance activities in Ontario and the prevention/diagnosis of Lyme disease.

10. Contribute to the development of a Lyme research agenda for Ontarians

*Key activities will include:*

**Contributing to a research agenda:** By participating in established federal Lyme disease research forums, such as the Best Brains Exchange sessions on Lyme, we will ensure that Ontario’s research priorities are represented and incorporated into the national research agenda.

**Supporting academic research on Lyme disease:** Opportunities for influencing and contributing to academic research agendas including provincial Lyme disease research priorities will be developed in collaboration with key stakeholders through interactive exchanges of information.
Next Steps

Building on the actions outlined in this report and those taken by a wide range of voluntary, non-profit organizations and health care providers and a continued commitment to working together, next steps will work to ensure that:

- Cases of Lyme disease are diagnosed and treated appropriately and as early as possible;
- Ontarians' awareness and knowledge about Lyme disease and how to prevent it increase; and,
- Patient-focused care is accessible with timely, evidence-based and supportive clinical management and care for those living with Lyme disease.

What Can You Do?

While the ministry is working to improve public awareness and ensure that health care providers have the necessary information on hand, Ontarians need to get involved and do their part in preventing Lyme disease. The ministry encourages all Ontarians to follow these simple steps:

- Access the current information about Lyme disease through the ministry’s website.
- Connect with parks and outdoor organizations, Lyme disease advocacy groups or your dedicated health care provider if you are seeking information about Lyme disease.
- Inform your health care provider if you think that you have been bitten by a tick. If someone you know has been bitten by a tick, encourage them to see their health care provider.
- Protect yourself, your family and those around you from Lyme disease.
For More Information

Telehealth Ontario
Toll free: 1-866-797-0000

General Inquiries

SERVICE ONTARIO
Toll free: 1-866-532-3161
In Toronto, (416) 314-5518
TTY: 1-800-387-5559
Hours of operation:
Monday to Friday, 8:30 a.m. – 5:00 p.m.

Media Inquiries

Toll free: 1-888-414-4774
In Toronto, (416) 314-6197
Email: media.moh@ontario.ca

Educational Resources

- Ontario.ca/Lyme
- Health Canada: Insect Repellents
- Public Health Reminder: Lyme Disease
- Healthy Canadians: Lyme Disease
- Health Canada: For Health Professionals
- Centers for Disease Control and Prevention
- Public Health Agency of Canada:Ticks and Lyme Disease
- Canada Communicable Disease Report
- Health Canada Advisory on Lyme disease Testing