**Media Lines**

**Launch of a Pan-Canadian Research Network on Lyme Disease**

**Context:** On October 4, 2018, Minister of Health Ginette Petitpas Taylor announced an investment of $4 million in a Pan-Canadian Research Network on Lyme Disease aimed at generating new knowledge to improve diagnosis and treatment for Canadians living with Lyme disease.

**Key Messages:**

* The Government of Canada recognizes that Lyme disease is emerging in many parts of the country, due in part to climate change, and we are committed to reducing the public health risk associated with this disease.
* The Canadian Institutes of Health Research and the Public Health Agency of Canada are working together to support much-needed research to address the gaps that exist for Lyme disease prevention and control, diagnosis and treatment options, and to improve the health of Canadians living with Lyme disease.
* Led by Dr. Kieran Moore from Queen’s University, the Pan-Canadian Research Network on Lyme Disease will bring together Lyme disease stakeholders—including researchers, clinicians and patients—to facilitate national collaboration and to generate new knowledge to improve the diagnosis, treatment and health outcomes for people with Lyme disease.
* We are proud to invest in a Research Network that focuses on partnerships among Lyme disease stakeholders to improve patient outcomes and access to care.
* We congratulate Dr. Kieran Moore from Queen’s University and his research team, and wish them success in their important work addressing Lyme disease.

**About Lyme disease:**

* Lyme disease, a multisystem infection caused by the bacteria *Borrelia burgdorferi* and transmitted through the bite of infected blacklegged ticks, is one of the most reported vector-borne diseases in North America. It is an emerging illness in Canada due to various factors, including the migration of ticks northward as the climate warms and as host vectors migrate. Research on Lyme disease is needed to fill evidence gaps that exist in:
* prevention and control;
* diagnosis and treatment options, and transmission dynamics;
* establishing the efficacy and limitations of current tests and methods to improve them; and
* helping inform an understanding of the causes, treatment and management options for patients who continue to experience persistent symptoms and chronic illness consistent with Lyme disease or similar ailments.
* Early symptoms of Lyme disease may include flu-like symptoms as well as a characteristic skin rash called *erythema migrans*.
* If left untreated, it can lead to more severe symptoms affecting the nervous, musculoskeletal and cardiovascular systems.
* The best way to prevent Lyme disease is to prevent tick bites. Canadians are encouraged to protect themselves by wearing clothing that covers their skin, using insect repellent containing DEET or Icaridin, and doing regular tick checks.
* If you are bitten by a tick, remove it immediately with tweezers and wash the bite area. Contact your healthcare provider if you do not feel well or are concerned about your health following a tick bite.

**On the Government of Canada’s actions:**

* The Government of Canada is addressing Lyme disease through education and awareness, national surveillance, laboratory testing, and research.
* The Federal Framework on Lyme Disease promotes the involvement of all stakeholders, including patients and their representatives, in ongoing dialogue to work towards reducing the risk of Lyme disease in Canada.
* The Government has committed $4 million to establish a Pan-Canadian Lyme Disease Research Network, with the aim of generating new knowledge to improve diagnosis and treatment.
* We have also invested in an [Infectious Diseases and Climate Change Fund](https://www.canada.ca/en/public-health/services/funding-opportunities/infectious-diseases-climate-change-fund.html), which supports additional stakeholder-led projects to address climate-driven infectious diseases such as Lyme disease.
* The Infectious Diseases and Climate Change Fund addresses the impact of climate change on human health in Canada by:
	+ increasing capacity to respond to the rising demands posed by climate-driven zoonotic (diseases that can be transmitted from animals and insects to humans), food-borne and water-borne infectious diseases;
	+ ensuring Canadians and communities have access to timely and accurate information to better understand their risks and take measures to prevent infection; and
	+ improving adaptability and/or resiliency to the health impacts of climate-driven infectious diseases, through surveillance and monitoring activities and access to education and awareness tools.
* Our federal laboratories are helping provinces and territories in their diagnostic testing for Lyme disease, and we are supporting public and professional education, data collection and research.
* The Government of Canada is committed to working with provincial and territorial health authorities and other partners, including those with lived experience, to inform Canadians of the health risks of contracting Lyme disease and ways to prevent it.

**On preliminary reporting of significant increase:**

* In an effort to better understand the spread and reach of Lyme disease, the Government of Canada collects data from its provincial and territorial partners about human cases of Lyme disease.
The Public Health Agency of Canada is reporting a significant national increase of human Lyme disease cases.
* As of July 16, 2018, 2,025 cases of Lyme disease were reported by the provinces to the Public Health Agency of Canada for 2017, as compared with 992 cases reported for 2016.
* Most of these reports are concentrated in known Lyme disease risk areas in Nova Scotia, Quebec and Ontario.

***If pressed on treatment guidelines:***

* In Canada, treatment guidelines for Lyme disease are developed by the medical community and fall outside the purview of the federal government.
* The Public Health Agency of Canada encourages physicians to diagnose and treat Lyme disease based on a history of possible exposure to infected blacklegged ticks (assessment of the outdoor activities that the individual has engaged in, and whether the individual has been in potential tick habitats), the clinical presentation, and laboratory test results when appropriate.

***If pressed on individuals seeking testing, diagnosis and treatment outside of what is recommended by Canadian health authorities:***

* Testing, diagnosis and treatment of Lyme disease in Canada falls under the jurisdiction of provincial and territorial governments.

**Questions and Answers:**

**Q1. What is the objective of the grant for the Research Network on Lyme Disease team?**

A1. We recognize that more research is needed on Lyme disease. That’s why in October 2017, CIHR and PHAC launched a funding opportunity to establish a Pan-Canadian Research Network on Lyme Disease. The Research Network aims to generate new knowledge to improve the diagnosis and treatment of Lyme disease in Canada.

**Q2. What will the Research Network on Lyme disease do?**

A2. The Research Network led by Dr. Kieran Moore from Queen’s University and his team will:

1. Build a national network on Lyme disease to facilitate and support national collaboration among Lyme disease stakeholders (researchers, clinicians, and patients) in resource and knowledge sharing:
	* Mobilize, strengthen and build capacity in the Lyme disease research community.
	* Develop innovative multidisciplinary curricula and training opportunities for students and professionals.
	* Facilitate and support translation and dissemination of new knowledge from bench to bedside to population in order to:
		+ improve clinical science and practice;
		+ foster policy changes, leading to transformative and measurable improvements in the development and implementation of evidence-informed practices, policies, services, products and programs; and
		+ improve patient outcomes, access to care and quality, efficiency and effectiveness of health care.
2. Develop a national cohort of patients in order to understand the association between serological and clinical phenomenology [need to define these terms]of Lyme disease on a longitudinal basis (including a biobank creation and maintenance).

The total amount available for this funding opportunity is $4 million—a maximum of $1 million per year for four years.

**Timelines**

* In May 2017, the Minister of Health announced that the Government of Canada, through the Canadian Institutes of Health Research (CIHR) and the Public Health Agency of Canada (PHAC), committed $4 million to establish a Research Network on Lyme Disease, with the aim of generating new knowledge on Lyme disease in Canada.
* In October 2017, CIHR, in partnership with PHAC, launched a request for applications for a Research Network on Lyme Disease team grant.
* On April 19, 2018, CIHR, in collaboration with PHAC, organized a workshop for registered applicants of the Research Network on Lyme Disease team grant. The workshop provided registered applicants with opportunities to strengthen their application and explore ways to work together to form a successful network across the country to advance Lyme disease research and achieve greater impact on health outcomes for people affected by Lyme disease.
* On October 4, 2018, the Minister of Health announced the launch of the Pan-Canadian Research Network on Lyme Disease.

Important dates related to the Research Network application process are below:

Registration deadline – 2018-03-06
Webinar on Strengthening Workshop – 2018-03-21
Strengthening Workshop – 2018-04-19
Application deadline – 2018-06-06
Notice of decision – 2018-09-27
Funding start date – 2018-09-01

CIHR funding decisions are made based on the recommendations from a peer review committee which comprises 13 independent individuals with various expertise and experiences, such as patients, patient engagement experts, researchers, clinician researchers, physicians and network/governance experts.

**Q3. When were the competition results made available?**

A3. On September 27, 2018, CIHR informed the applicants of the competition results. The funding for the Pan-Canadian Research Network on Lyme Disease started on September 1, 2018.

**Q4. Why did you extend the application deadline by three months?**

A4. In an effort to provide more support to Canadian researchers interested in the Research Network on Lyme Disease funding opportunity, CIHR and PHAC extended the application deadline by three months. The application deadline of March 6 was changed to a registration deadline. All registered applicants were invited to an information webinar on March 21, 2018, which was organized by CIHR and PHAC, and provided information on a strengthening workshop.

Following the webinar, registered applicants were required to participate in a strengthening workshop, which was held on April 19, 2018, in Ottawa, to help them develop their application. The final step for applicants was to complete and submit their application to CIHR via ResearchNet. The deadline for all applications was June 6, 2018.

**Q5. What benefits did the strengthening workshop offer?**

A5. The workshop provided an opportunity for the researchers and stakeholders to:

* learn from the experience and insights of expert speakers and other stakeholders;
* explore strategies and tools for strengthening their full applications; and
* share perspectives on the Research Network on Lyme Disease and identify mutually beneficial opportunities for collaboration.

Participants included the Nominated Principal Applicant (NPA) as well as key team members, CIHR and PHAC senior management, and stakeholders including patient representatives.

Patient representatives attending the workshop had the opportunity to share patient experiences with Lyme disease, explore ways to engage in research, and discuss the impact of Lyme disease on patients and their families.

CIHR and PHAC value patient and citizen engagement in the research process. This engagement was essential in the development of an informed, sustainable Research Network and will support a more coordinated approach to diagnosing and treating Lyme disease in Canada.