

PATIENT ROUNDTABLE ON LYME DISEASE

September 13, 2017



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PATIENT ROUNDTABLE ON LYME DISEASE

WELCOME AND OPENING REMARKS

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MEETING OBJECTIVES

1. To discuss the Federal Action Plan on Lyme Disease
2. To engage with Lyme disease patient representatives on the implementation of the Federal Action Plan



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FEDERAL LYME DISEASE ACTION PLAN

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TACKLING **LYME** DISEASE IN CANADA



We are focusing our actions in **3 AREAS:**



SURVEILLANCE

- ▶ Strengthen current efforts and create a national tick surveillance system
- ▶ Expand data collection to include people who may not meet the formal case definition for Lyme disease
- ▶ Conduct analysis of the costs associated with Lyme disease
- ▶ Continue to assess the current and future risk of Lyme disease in Canada and work with our partners on innovative methods on surveillance



EDUCATION AND AWARENESS

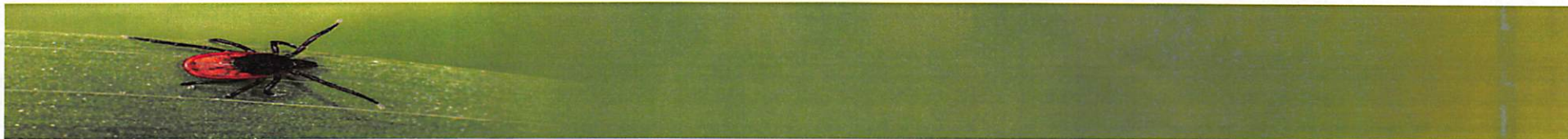
- ▶ Support health professionals by developing education materials in prevention and diagnosis
- ▶ Enhance national awareness about Lyme disease through education and awareness campaigns



GUIDELINES AND BEST PRACTICES

- ▶ Inform guidelines and best practices through the creation of a Lyme disease research network
- ▶ Support laboratory diagnostic testing
- ▶ Work with international partners to share best practices
- ▶ Consult on innovative and evidence-based ways to address patients' needs

Handy



SURVEILLANCE

Action Plan Activities

- Integrate and disseminate innovative methods and best practices for human surveillance among an expanded group of partners.
- Collect human surveillance data in Canada for people who do not meet the case definition for probable or confirmed Lyme disease.
- Perform an analysis of the costs associated with Lyme disease.
- Develop a national tick-borne surveillance system that includes Lyme disease and other possible co-infections.

Progress to date

- Rollout of 2017 surveillance activities on human cases of Lyme disease and ticks.

Planning & Consultations

- Development of methodologies to collect human surveillance data in Canada for people who do not meet the case definition and for performing an analysis of the costs associated with Lyme disease -- consultations to be held with stakeholders.
- Development of surveillance activities for other tick-borne illnesses, including national case definition -- consultations to be held with stakeholders.



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EDUCATION AND AWARENESS

Action Plan Activities

- Support partners to develop early detection/early diagnosis education materials, with a focus on high risk groups, to assist front-line health professionals and public health authorities in the prevention and diagnosis of Lyme disease.
- Develop a national tick and Lyme disease education and awareness campaign, in collaboration with partners, that addresses:
 - Tick bite prevention and early intervention
 - Recognition of Lyme disease symptoms, so that patients can seek help and front-line professionals can perform early diagnosis and treatment

Progress to date

- Rollout of 2017 Lyme disease education and awareness activities including: (i) education and awareness posters, pamphlets, handouts and videos (PHAC Web site); and (2) Parks Canada signage.

Planning & Consultations

- Consultations initiated with select national health professional associations to explore expanding education initiatives on Lyme disease (e.g. family physicians).
- Development of 2018-2020 Lyme disease public awareness plan – broad consultations to be held with range of stakeholders.





GUIDELINES AND BEST PRACTICES

Action Plan Activities

- Establish a Lyme disease research network.
- Work with international public health partners to share best practices and disseminate domestically.
- Continue to support front-line health professionals and provincial laboratories in the laboratory diagnosis of Lyme disease.
- Consult with provincial and territorial health care regulatory authorities on innovative, evidence-based approaches to address the needs of patients.

Progress to date

- Funding for research network announced by the Minister of Health in May 2017.
- Planning and Dissemination Grants launched by CIHR in July 2017.
- Pre-announcement of Lyme disease Research Network Request for Applications by CIHR in September 2017.



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UPDATE ON LYME DISEASE RESEARCH NETWORK

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ROUNDTABLE DISCUSSION

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GUIDELINES AND BEST PRACTICES

- The Public Health Agency of Canada is considering sharing best practices on prevention, awareness and detection of Lyme disease.
 - Are you aware of any innovative approaches and best practices in Canada or internationally that would benefit Lyme disease patients across Canada?
- In anticipation of the public launch of the Lyme Disease Research Network Request for Applications:
 - What researchers/research groups are patients already connected with?
 - Where do you see opportunities for strengthening connections with the Canadian Lyme disease research community?



SURVEILLANCE

- The Public Health Agency of Canada will be working to explore the epidemiology and trends of people who do not meet the current case definition. The Public Health Agency of Canada is also planning to perform an analysis of the costs associated with Lyme disease.
 - Are you aware of any data/work that the Public Health Agency of Canada could build on and any suggestions on how this work could proceed?
 - What would you see being done with this information once collected?



EDUCATION AND AWARENESS

- The Public Health Agency of Canada will be working with health professional associations to develop tools to raise awareness of Lyme disease, in particular, to assist front-line health professionals and public health authorities in the prevention, awareness, and detection of Lyme disease. We will also be working with partners to develop education and awareness campaigns for the public and specific high risk groups.
 - What role are patient groups currently playing in Lyme disease education and awareness of health professionals and the public?
 - What specifically would you want to focus on for front-line workers when they see suspected/probable Lyme disease cases or Lyme disease patients?
 - Which health professional groups should be targeted as a priority?
 - Who should be the focus of the public education campaigns?



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CLOSING REMARKS AND ADJOURNMENT

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CIHR IRSC

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Patient Roundtable on Lyme Disease

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Discoveries for life / Découvertes pour la vie



Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Canada

Agenda



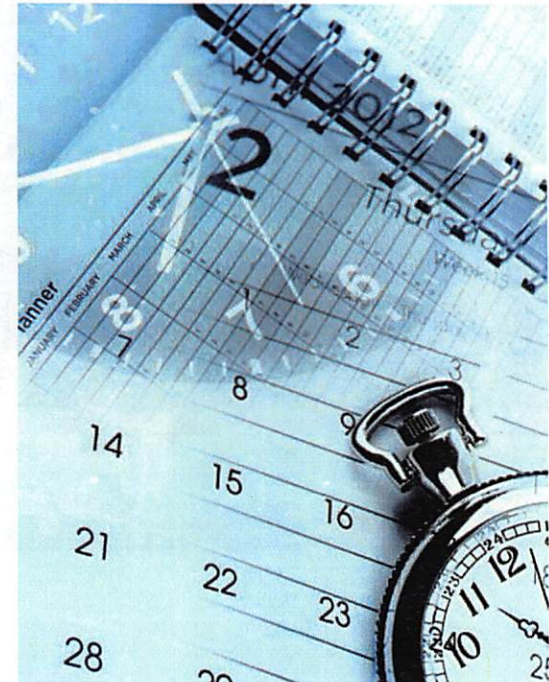
Introduction to CIHR



Request for Applications (RFA) and peer review process overview



Lyme Disease Research Network update



Introduction to CIHR

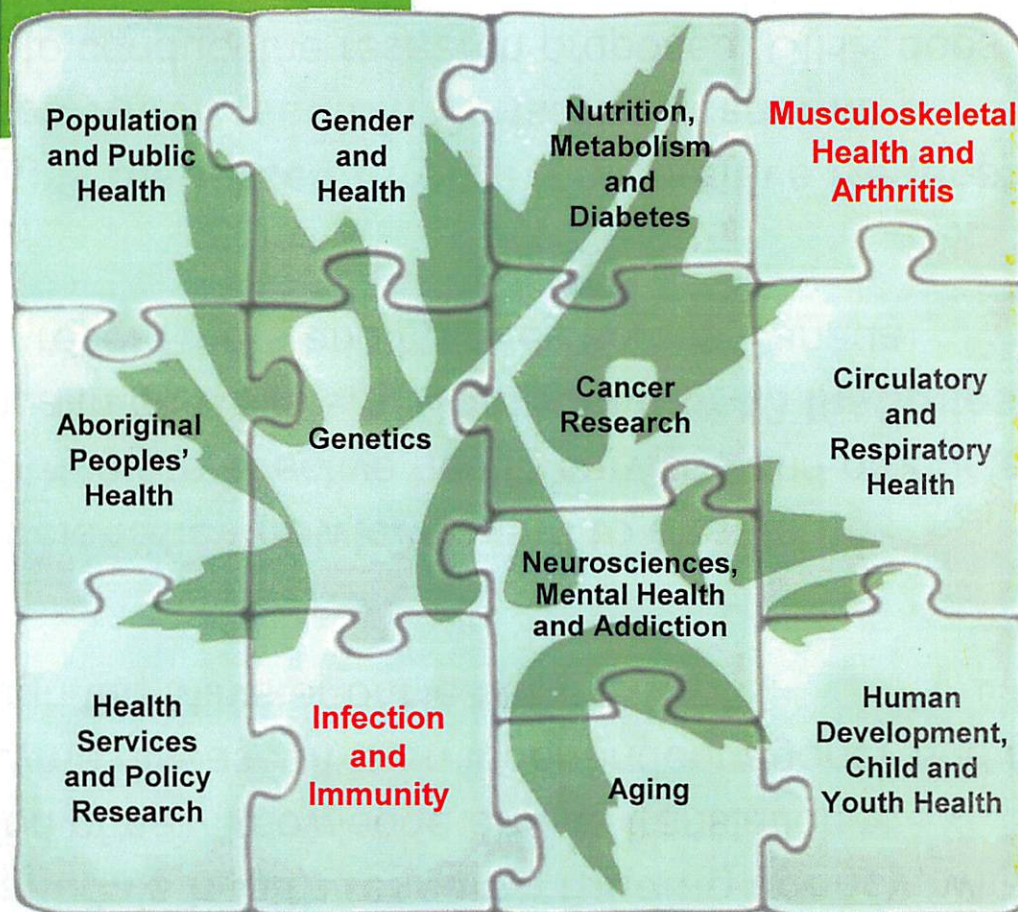
- **CIHR is the Government of Canada's health research funding agency**, with a mandate to support the creation of new knowledge and its translation to various health areas including Lyme disease. It is an independent agency and is accountable to Parliament through the Minister of Health.
- **Our mission is to create new scientific knowledge and to enable its translation into improved health**, more effective health services and products, and a strengthened Canadian health care system. **Composed of 13 Institutes**, CIHR provides support to health researchers and trainees across Canada.
- **The majority of CIHR's funding is disbursed through competitive Request for Application (RFA) processes which result in Canadian academic researchers receiving a grant** to conduct the research proposed. CIHR does not conduct research "in-house."

CIHR Institutes

Created in 2000, CIHR is a unique model for health research.

With its 13 Institutes, CIHR has become a meeting ground for Canada's health research community.

Scientific leadership for matters concerning Lyme disease is provided by CIHR's Institute of Infection and Immunity and Institute of Musculoskeletal Health and Arthritis.



Patient Engagement at CIHR

- **Patient engagement is an important and growing part of the way CIHR supports research.** Our agency's strategic plan, "*Health Research Roadmap II*" (<http://www.cihr-irsc.gc.ca/e/48964.html>), contains a commitment to embedding the perspectives of patients in our business.
- The term 'patient' at CIHR broadly means **individuals with personal experience of a health issue, as well as their informal caregivers such as family and friends.**
- Patient engagement at CIHR is the **meaningful and active collaboration of patients in decision-making, priority-setting, conducting research, and applying the results** to our health system.

Rather than research *for* or *about* patients, patient engagement involves research **by and with** patients.

Patient Engagement at CIHR

Guiding principles of patient engagement

Inclusiveness

Patient engagement in research integrates a true **diversity** of patient perspectives.

Support

Adequate support and flexibility are provided to patients **to ensure they can contribute fully**.

Mutual Respect

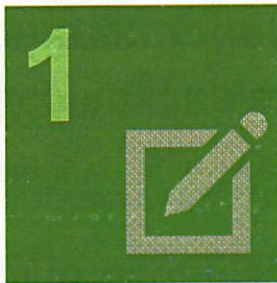
Patients, researchers and health care professionals **acknowledge and value** each other's expertise and experiential knowledge.

Co-Build

Patients, researchers and health care professionals **work together** to identify problems, set priorities and work together to carry out solutions.

To learn more, see the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework, <http://www.cihr-irsc.gc.ca/e/48413.html>.

Request for Applications (RFA) process



Research Need Identified

- Identified by CIHR Institute, government, or other stakeholders
- Internal approval of budget and of RFA launch
- RFA is developed by CIHR and competition partners (if applicable)



RFA Launched

- RFA posted publicly on CIHR's web site
- A webinar is held to review the RFA and answer questions
- CIHR's Contact Centre is a single point of contact for applicant questions to ensure accurate and consistent information



Applications peer reviewed and grants awarded

- Experts with various perspectives meet and make funding recommendations according to the evaluation criteria in the RFA
- CIHR awards grants for a specific amount and duration following peer review recommendations
- Information on successful applicants is posted publicly on CIHR's web site

Peer review process

- **Peer review refers to the process used to review applications submitted for grant funding.** CIHR's peer review process is supported by experts (peer reviewers) with various perspectives from the health research community (e.g. health professionals, patients and citizens, researchers). To learn more, see Peer Review Overview, <http://www.cihr-irsc.gc.ca/e/39380.html>.
- **Applications are assigned to reviewers** with the required experience and/or expertise (individual or collective) to properly assess the quality of the applications based on the objectives of the RFA and its evaluation criteria, and in accordance with the [COI and Confidentiality Policy of the Federal Research Funding Organizations](#).
- Generally, applications are reviewed at home by reviewers and then discussed as a committee at a in-person meeting. **Peer reviewers make funding recommendations to CIHR based on evaluation criteria in the RFA.** Applicants receive a notice of decision document along with reviewer reports.

RFA and peer review considerations

Fairness and absence of conflict of interest (COI):

- CIHR strives to ensure all potential applicants have access to the same RFA information and related resources at the same time, to avoid one group having an undue advantage over another.
- Individuals participating in an application to a specific RFA generally do not act as peer reviewers for that RFA to avoid real or perceived COI.
- Funding decisions are recommended to CIHR by peer reviewers and are made independently from the Minister of Health. CIHR staff do not participate in recommending applications for funding.

CIHR's involvement in grant activities:

- A grant is a transfer payment from CIHR that continues as long as eligibility and other conditions of funding outlined in the RFA are met.
- Grantees required to provide grant reports to CIHR as part of CIHR's accountability to Canadians and requirement to report on results.
- CIHR may be involved in oversight and governance activities to ensure conditions of funding are met, but CIHR does not direct the research activities of CIHR grant funded researchers, including Networks.

Institute of Infection and Immunity



III Mandate

The Institute of Infection and Immunity (III) supports research and helps to build research capacity in the areas of infectious disease and the body's immune system. Through the Institute's programs, researchers address a wide range of health concerns related to infection and immunity including disease mechanisms, disease prevention and treatment, and health promotion through public policy.



Research excellence and capacity development

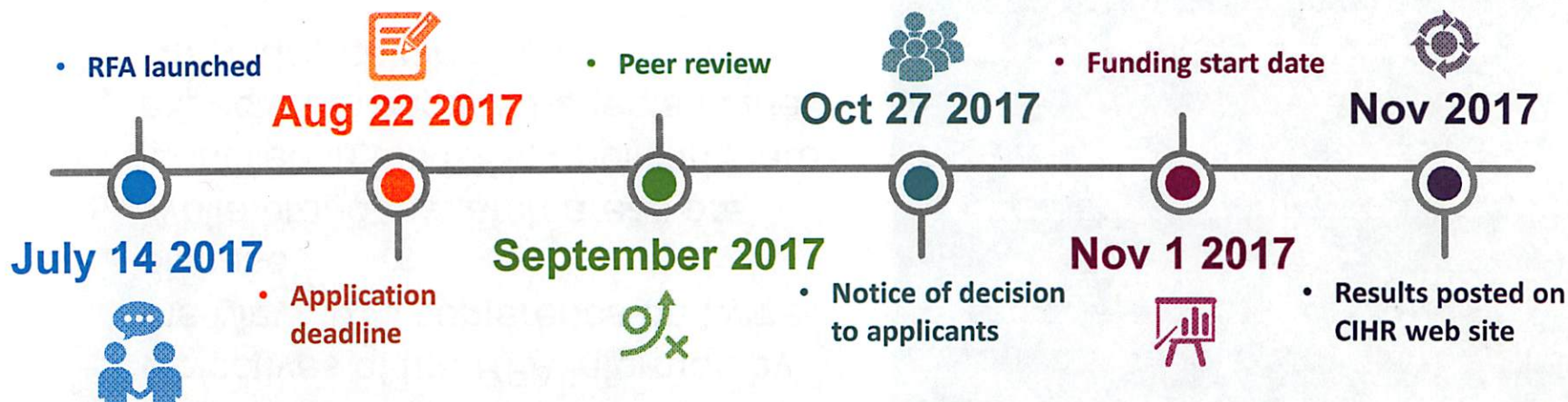
Priority 1: Preparing for and responding to existing and emerging threats

Priority 2: Integrating Infection and Immunity Knowledge in the Control and Prevention of Chronic Disease

Lyme Disease Planning and Dissemination RFA

- 2 grants available (\$30K each for 1 year)
- Purpose to begin mobilizing the community by providing funding for planning activities that support the development of an application to the Lyme Disease Research Network RFA

- Must include a variety of stakeholders (including patients) and have a national scope
- Date of activity and invitees determined by the applicants
- Not required to receive a planning and dissemination grant to be eligible to apply to Network RFA



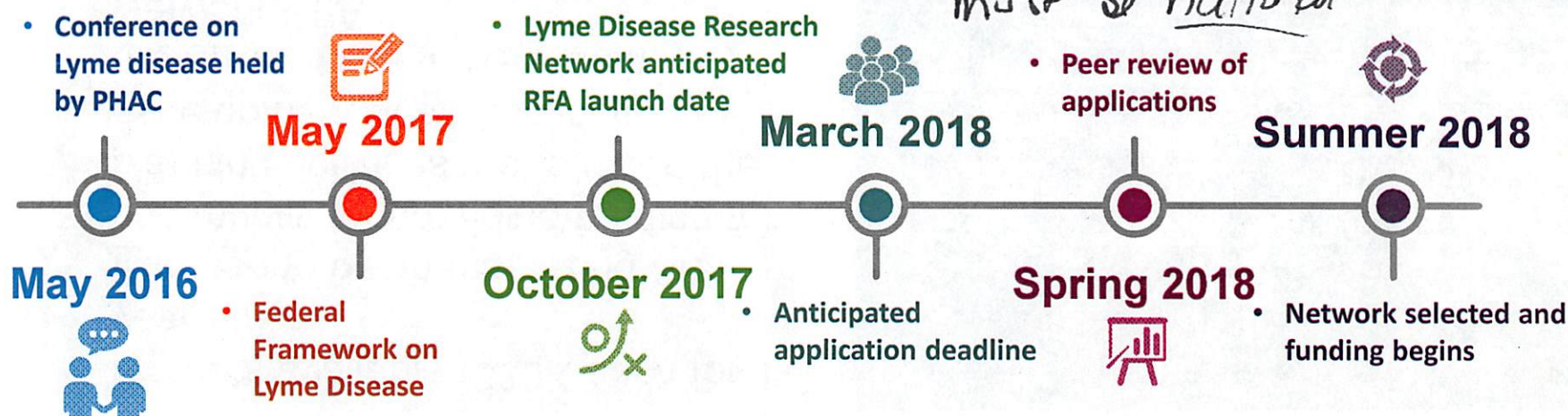
Lyme Disease Research Network RFA

2 objectives

- Objectives of the RFA informed by the May 2016 conference on Lyme disease
- While broad research areas are identified in the RFA, applicants are expected to engage patients in the Network's governance

- 1 grant, \$4M over 5 fiscal years
- National network will support research collaboration and knowledge sharing and develop a national cohort of patients to generate new knowledge to improve patient outcomes
- Application must include a variety of stakeholders, including patients

must be national



Next steps to engage in the Network RFA

- Consult the Network RFA pre-announcement, full RFA to be posted on [CIHR's web site](#) in October 2017
- Participate in the Lyme Disease Network RFA applicant webinar (to be held shortly after the Network RFA is posted, dates will be in the RFA)
- Watch CIHR's [Funding Decisions Notification](#) page for information on who was funded through the Lyme Planning and Dissemination Grants (to be posted Nov 2017)
- Connect with researchers – patients must be part of the application:
 - Connect through your own networks, both direct and indirect (e.g. through health professionals who specialize in Lyme disease)
 - Search CIHR's [Funding Decisions Database](#) for Lyme disease researchers
 - Provincial health research funders and universities have similar databases



CIHR IRSC

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



THANK YOU!

Discoveries for life / Découvertes pour la vie

For RFA-related questions:

CIHR Contact Centre

Email: support@cihr-irsc.gc.ca

Phone: 1-888-603-4178

For all other inquiries:

Environments and Health Initiative

Email: EHSI@cihr-irsc.gc.ca



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