



**CANADIAN LYME DISEASE**  
RESEARCH NETWORK

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# **JUNE 2022**

Canadian Lyme Disease Research Network  
221 Portsmouth Avenue  
Kingston, Ontario K7M 1V5  
[www.clydrn.ca](http://www.clydrn.ca)

# PILLAR UPDATES

## Pillar 1

### DIAGNOSTICS

*The consultant continues leading the discussion between the scientific leads and patient and family partners. First draft of the research proposal has been created and vetted to Pillar 1 members for their feedback. Expecting the next revised draft to arrive soon for additional input before being circulated to PCAC members. The project will be using historical samples stored in the provincial (BC and ON) labs' freezers as well as collecting new prospective samples during the 2023 Lyme disease season.*

## Pillar 2

### PREVENTION AND RISK REDUCTION

*The Surveillance Working Group has doubled the scope of their planned surveillance sites for this spring/summer 2022. The veterinary surveillance program that began as a pilot program last summer will continue this summer with the same number of sites. Data analysis completed for the retrospective case-control study and writing up the manuscript. The prospective case-control study is being launched at both recruitment sites. The Innovation/Intervention Working Group finalized their protocol and continues to recruit students and trainees to help roll out the project. The Modelling Working Group completed a proposal for use of their seed funds; the proposal has been vetted through PCAC members and is being reviewed by the CLyDRN Executive Committee for approval.*

*Improve prevention, diagnosis, and treatment of LD in Canada*

## Pillar 3

### CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

#### **COHORT Study-Kingston, ON Site:**

*10 participants have been enrolled (consented);  
9 participants completed their Baseline visit;  
8 participants completed 1-month, 3-month, and  
6-month follow-up visits; 6 participants completed  
9-month follow-up visit; 2 participants dropped out;  
12-month follow-up visits will commence  
between June-August 2022.*

#### **CLYME (Biobank) Study-Kingston, ON Site:**

*23 participants have been enrolled (consented);  
22 participants completed Baseline visit;  
16 participants completed 1-month follow-up visit;  
5 participants dropped out.*

*The Kingston site re-launched participant recruitment on May 1, 2022 for Lyme disease cohorts and healthy controls. The Lunenburg site will commence recruitment very soon.*

## Pillar 4

### PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

*Conducted 43 virtual interviews with national healthcare practitioners. Knowledge Translation Porthole discussions on hold. The barriers to preventative behaviours study have begun coding the data from the 22 focus group sessions carried out across BC, MB, ON, QC, and NS. Data analysis will follow. The Pan-Canadian survey study has received REB ethical clearance. The study is expected to begin late June/early July 2022. Currently exploring funding to develop a tick bite prevention bilingual website in Quebec. Brokered dialogue protocol was finalized and received REB ethical clearance. The doctoral project on Indigenous experiences and perspectives on Lyme disease continues development. The Community Engagement Committee has been formed: seven (7) community members are undergoing orientation.*



# COMMITTEE UPDATES

## CC

### COMMUNICATIONS COMMITTEE

*Activities still on hold.*

*Looking for Network members to join this committee to help roll out activities. If interested in joining this committee, please reach out to the CLyDRN Network Management Office at [clydrn@gmail.com](mailto:clydrn@gmail.com).*

## PCAC

### PATIENT AND COMMUNITY ADVISORY COMMITTEE

*There are >40 active members, with several new members pending orientation. PCAC held advisory roles by providing feedback and input through surveys and discussions with Pillar 1-4 and the Project Grants Committee with different levels of engagement (co-design and collaboration). Various PCAC members hold leadership roles on the Executive Committee, Pillar Leads Committee, and Event Planning Committee (AGM and Lyme disease awareness events). PCAC is leading the implementation of the GRIPP2 tool for capturing patient engagement in research projects.*

*Improve prevention, diagnosis, and treatment of LD in Canada*

## PGC

### PROJECT GRANTS COMMITTEE

*The Fundraising Committee changed its name to Project Grants Committee (PGC). PGC will be a planning committee with a mandate to find ways to help translate priorities identified from our patients, family caregivers, and community stakeholders through engagement and collaboration into fundable research grants. The committee is still looking for members to join to help launch and support this important initiative for our Network. PGC will meet quarterly. If interested in joining, please reach out to **Dr. Rob Colautti** ([robert.colautti@queensu.ca](mailto:robert.colautti@queensu.ca)) and **Dr. Clara Juando-Prats** ([clara.juando@utoronto.ca](mailto:clara.juando@utoronto.ca)).*

*The New Frontiers Exploration grant was not successful in being funded; will look to re-apply in future competitions. Recently presented at Science Rendezvous: a virtual and in-person event for children and families held at various sites across Canada throughout May to help raise awareness about tick safety and Lyme disease. Will be presenting on the accomplishments of the Network to date, including the research projects under PGC, at the Kingston-Syracuse Pathway Conference, which is a collaboration between Queen's and SUNY (State University of New York) to advance cross-border collaborations in research, innovation, and economic development. There is a new Lyme disease survey posted on [myLyme.ca](http://myLyme.ca).*

## TAC

### TRAINEE ADVANCEMENT COMMITTEE

*TAC held two webinar this spring: "Communicating with Media" and "Veterinary aspects of Lyme disease". If anyone is interested in presenting to TAC, please reach out to **Dr. Katie Clow** ([kclow@uoguelph.ca](mailto:kclow@uoguelph.ca)) and **Natasha Bowser** ([natasha.nofal@umontreal.ca](mailto:natasha.nofal@umontreal.ca)).*



# RESEARCH ARTICLES, BOOKS & INTERVIEWS

## LYME AWARENESS

**Interview:** CHCH-Inside the Story-March 28, 2022-As tick season expands, here's how to protect yourself from Lyme disease: <https://www.youtube.com/watch?v=I4TGOPXoxqg>. Reporter Niki Anastasakis interviews Dr. Rob Colautti and Jennifer Kelly (patient partner). Jennifer shares her story of awareness about a tick bite that led to years of health setbacks after contracting Lyme disease.

## CLIMATE CHANGE

**Report:** Health Canada-Health of Canadians in a Changing Climate-Advancing our Knowledge for Action: <https://changingclimate.ca/health-in-a-changing-climate/>

## LYME DISEASE

**Website Update:** In the summer/fall 2020 the Public Health Agency of Canada (PHAC) consulted with stakeholders from provincial/territorial Ministries of Health, researchers, health professionals, health professional associations, patient groups, and person with lived experience. As a result of the feedback received, the website now contains improved navigation, up-to-date scientific evidence, clear directions on tick bite prevention, answers to the most commonly asked questions, and information and available data on Lyme disease: <https://www.canada.ca/en/public-health/services/diseases/lyme-disease.html>. Areas identified by PHAC requiring additional information/clarity in the future include: comprehensive list of signs and symptoms, such as adding information on Lyme carditis; images of erythema migrans (EM) rashes on dark skin tones; explanation of laboratory diagnosis (testing) and its limitations; risks of getting Lyme disease; clinical diagnosis of Lyme disease; tick identification, testing, and attachment time; new interactive risk area maps; updated links to provincial/territorial resources; and links to Canadian resources for Lyme disease management.

## TAC Webinars

To access the Trainee Advancement Committee (TAC) webinars (videos and presentations), please go to [www.clydrn.ca](http://www.clydrn.ca) and click "Login" at the top. Enter your email (username) and password and then follow this path to view the video and presentation slides: *Resources-Committees-Training*. There are two new videos to watch: *Communicating with Media* (March 9<sup>th</sup>, 2022) and *Veterinary aspects of Lyme disease* (June 23<sup>rd</sup>, 2022).

## Publications

Have you recently published (journal article, book chapter, lead author/editor of a book, technical reports, policy briefs or policy guidelines)? Have you recently had one of your presentations or interviews with a journalist video-recorded? Please share your news and links with the CLyDRN Network Management Office so we can share with our members in future newsletters to help raise awareness and celebrate the impact of our members' work.

## Member Annual Reporting Form

The annual reporting form was sent to all our CLyDRN Members via email to help us collect some metrics about our Network for our annual progress report to CIHR. We encourage all our CLyDRN Members to take a moment to complete the form and return to the CLyDRN Network Management Office by June 30, 2022. All returned forms by the due date will be entered into a draw for 1 of 4 \$25 Starbucks electronic gift cards. Thank you.

## CLyDRN Members Portal

If you have not yet created a user account on the CLyDRN website, please go to [www.clydrn.ca](http://www.clydrn.ca) and click on "Register" at the top. Once you register, CLyDRN Network Management Office will get an email to accept your membership. Once this occurs, you can click on "Login" and enter your email (username) and password to access the members portal. If you have a user account and have forgotten your password, simply click on "Login" and click on "Forget Your Password".



# Do you have a story to share about Lyme disease? Let's Talk!

Researchers at St. Michael's Hospital and the Canadian Lyme Disease Research Network are conducting a study.

## We are looking to speak with:

- Persons with lived experience of Lyme disease
- Family or caregivers of people living with Lyme disease
- Healthcare practitioners
- Lyme disease researchers
- Policy and decision makers



**Participate in a 1-hour interview over the phone or zoom and share your experiences of and perspectives on, diagnosis, treatment and management of Lyme disease in Canada.**

Participants will receive a \$25 gift card. For more information or to participate, please contact Lisa Dias at [lisa.dias@unityhealth.to](mailto:lisa.dias@unityhealth.to) or 416-360-4000 ext. 49312

Study Title: Understanding Stakeholder Perspectives on Lyme Disease in Canada, REB: #22-049  
*Please note that email is not secure. Emails can be intercepted, viewed, changed or saved by others. Only send information to this address that you do not feel is sensitive.*



## LYME DISEASE AWARENESS EVENT (May 2022)

Thank you to our 22 speakers who presented at this year's Lyme Disease Awareness Event. Presentations occurred May 1<sup>st</sup>-31<sup>st</sup>, 2022 on various Lyme disease and tick-borne disease topics. The event was a huge success with ~40-45 individuals virtually connecting into the presentations at each session. The Agenda Program can be found here: <https://www.clydrn.ca/wp-content/uploads/2022/04/CLyDRN-Virtual-Lyme-Disease-Awareness-Event-May-2022-Program-FINAL-General-Distribution-1.pdf>.

To access the 17 video presentations, please go to [www.clydrn.ca](http://www.clydrn.ca) and click "Login" at the top. Enter your email (username) and password and then follow this path to view the video and presentation slides: *News-News Network Update*. We will reach out to the two presenters who had to cancel to see if they are able to re-schedule their talk for a future webinar session...stay tuned!

Throughout the month of May, members could submit photos of wearing green or submit a photo of a piece of artwork to help raise awareness for Lyme disease. All entries received were entered into a draw for a chance to win a \$25 Starbucks e-gift card. Our six draw winners are listed below....

### Draw Winners...



Matthew



Stefan



Jamie



Mary Lee



Terrie



Andrew





## SAVE the DATE...

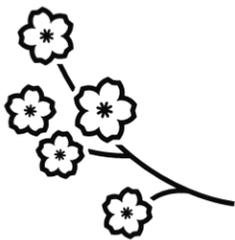
### In-Person 2022 MEMBERS AGM & SCIENTIFIC MEETINGS

This year's event is scheduled for **October 4<sup>th</sup>-6<sup>th</sup>, 2022 in Toronto, Ontario, Canada.**

We are in the process of completing plans for our first major in-person event in over three years. We will provide an outline of the planned sessions and workshops by the end of June 2022. Agenda, registration, and hotel accommodations to follow closer to the event.

Please take a moment to complete this quick survey for gauging preliminary interest from our CLyDRN members in attending this important collaborative and engaging event to continue to learn, ask questions, and exchange knowledge and dialogue on Lyme disease and tick-borne diseases:

**<https://www.surveymonkey.com/r/BSCLGR5>**.



### CLyDRN NETWORK MANAGEMENT OFFICE

**Veronica Harris-McAllister**  
Network Manager

E: Veronica.Harris-McAllister@kflaph.ca  
T: 613-549-1232, ext. 1601

