



CANADIAN LYME DISEASE
RESEARCH NETWORK

IN THIS ISSUE...

Pillar Updates
Committee Updates
Research Projects
Lyme Disease Awareness Event
Annual General Meeting 2021
CLyDRN Members Portal
TAC Webinars
Publications
Member Annual Report Form
Contact Us

MEMBERS NEWSLETTER

MARCH 2021

Canadian Lyme Disease Research Network
221 Portsmouth Avenue
Kingston, Ontario K7M 1V5
www.clydrn.ca

PILLAR UPDATES

Pillar 1

DIAGNOSTICS

The top 3 research priorities have been identified by PCAC and have been shared with the Pillar 1 scientists. A potential project identified by PCAC is to compare a pool of tests conducted within and outside Canada for diagnosing Lyme disease. The next step to move forward on this potential project would involve a survey on the current landscape to inventory what is out there (current and what is new/emerging). Pillar 1 is currently working on identifying the scientist to help lead the development of the project with PCAC.

Pillar 2

PREVENTION AND RISK REDUCTION

The surveillance working group has initiated processes to refine the multi-criteria decision analysis for selection of additional sentinel sites for expansion in the spring/summer 2021. The Public Health Agency of Canada will be providing additional funding to help increase the surveillance capacity under Pillar 2. The innovation working group has completed a draft proposal for use of the Pillar 2 seed funds and are hoping to get the project initiated this summer. The prospective case-control study will begin in the spring 2021.

Pillar 3

CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

The COHORT and CLYME (biobank) studies will be launching in the spring 2021 at the Kingston, ON site (Dr. Michael McDonnell is the local Lead PI). Both studies are expected to be launched at the Lunenburg, NS site (Dr. Elizabeth Stringer is the local Lead PI) in the summer/fall 2021. Pillar 3 continues to hold biweekly team meetings.

Improve prevention, diagnosis, and treatment of LD in Canada

Pillar 4

PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

Systematic review completed and is waiting to be published. Grey literature review is ongoing and slightly delayed due to the unexpected number of resources (>160 resources have been reviewed). 13 interviews have occurred for the healthcare practitioner project. Discussions related to the knowledge translation and training (KTT) porthole have begun. Starting in the spring 2021 an internal working group that will include patient partners and community stakeholders will start mapping the approach and design of the KTT porthole. Qualitative focus group discussions will be conducted online versus in person this summer if travel/research restrictions are still in place. The Pan-Canadian survey has been pushed to 2022. Brokered dialogue project is working on the REB submission with PCAC and finalizing the design of the protocol. To move forward on this project, a first phase of in-depth audio recorded interviews will be completed. The data collected will serve as foundation for the filmed brokered dialogue portion of the project (Phase 2) that will occur once in-person interviews can be completed. Stakeholder mapping with PCAC and Network Leads was completed for the community engagement project.



COMMITTEE UPDATES

PCAC

PATIENT AND COMMUNITY ADVISORY COMMITTEE

There are 31 active members. 5 new members have joined PCAC in the past few months and have undergone orientation. PCAC continues to support all the pillar research activities.

CC

COMMUNICATIONS COMMITTEE

*Activities currently on hold.
Looking for new members to join this committee to help roll out activities. If interested in joining this committee, please reach out to the Network Management Office.*

Improve prevention, diagnosis, and treatment of LD in Canada

FC

FUNDRAISING COMMITTEE

*Committee is looking for new members to join this committee to help roll out fundraising activities. If interested, please reach out to
Dr. Rob Colautti
(robert.colautti@queensu.ca).*

TAC

TRAINING ADVISORY COMMITTEE

Olivia Tardy and Isabelle Couloigner will be co-presenting “Modelling the spread of ticks and tick-borne pathogens” on March 25th. Rylan Egan and Madison Robertson will be co-presenting “Health care practitioner perspectives on diagnosis and treatment” on April 29th.



RESEARCH PROJECTS...

Seeking Input and Participants

CHRONIC LYME DISEASE SURVEY

The Pain Lab at Queen's University invites Lyme disease patients to participate in a short survey study to better understand the physical and mental aspects of living with Chronic Lyme Disease (CLD). This research will help design future support programs to help improve the well-being of people living with CLD.

If you have any questions related to this study, please email **Dr. Dean Tripp** (dean.tripp@queensu.ca) and **Maddie Gravelle** (16mnkg@queensu.ca). The survey can be found here: https://queensu.qualtrics.com/jfe/form/SV_0dESA8MOywfYm5

HEALTHCARE PRACTITIONER INTERVIEWS

Pillar 4 is currently looking for physicians to participate in a confidential study focused on better understanding the perspectives, experiences, beliefs, and knowledge of health practitioners regarding Lyme Disease (LD) in Canada. If interested in this study, participants will be invited to a 30-45-minute interview focused on their experiences, perspectives, and knowledge of diagnosing and treating individuals with Lyme disease. Participants will also receive a \$100 participant stipend for their time. If you are interested in this study, or would like to know more, please email **Madison Robertson** (12mar9@queensu.ca).

TICK-BITE SURVEY

The purpose of the study is to better understand the symptoms experienced by people who have been bitten by ticks and to better understand how experiences with healthcare practitioners and pre-existing conditions affects these groups of people with similar reported tick-bite related symptoms. To learn more about the study go to:

myLyme.ca. If you have any questions related to this study, please email **Emilie Norris-Roozmon** (14enr2@queensu.ca). The survey can be found here: https://queensu.qualtrics.com/jfe/form/SV_0enCON30GWPv7GB

PATIENT AND FAMILY MEMBER PERSPECTIVES SURVEY

Pillar 4 is currently conducting a research project to better understand the perspectives, experiences, beliefs, and knowledge of health practitioners regarding Lyme Disease (LD) in Canada. A very important step in their research study will be to identify healthcare practitioners to interview. LD patients' and their family members' recommendations regarding healthcare practitioners with which they have had challenging or effective LD experiences is a key step to this process. The survey will focus on patient and family member experiences with healthcare practitioners, specific to LD. Participating in this study will require the completion of one anonymous online survey and should take approximately 10-20 minutes of your time. If you have any questions related to this study, please email **Madison Robertson** (12mar9@queensu.ca). The survey can be found here: https://queensu.qualtrics.com/jfe/form/SV_57jWsGBHBm00Kff

GREY LITERATURE REVIEW

Pillar 4 is currently conducting a Grey Literature review to identify continuing professional development, training, and knowledge translation resources on Lyme Disease (LD) for healthcare practitioners and are asking for your help in identifying these resources.

If you wish to participate or have any questions related to this study, please email **Dr. Angela Coderre-Ball** (mca@queensu.ca) listing any LD resources and/or training opportunities you are aware of or have utilized. Alternatively you can also complete the following survey to provide the information: https://queensu.qualtrics.com/jfe/form/SV_eG8DrMOKjzzEZHT

ONE HEALTH SURVEY

Dr. Katie Clow and her research team will be establishing a Veterinary Sentinel Network. Anyone who works in any sector that deals with the health and wellbeing of humans, animals, or the environment, are invited to participate in an online survey on the strengths, challenges and needs of key stakeholders in a cross-sectoral and multidisciplinary One Health approach to tick and tick-borne disease surveillance in Canada. The findings from this survey will help develop and evaluate a One Health approach to surveillance of ticks and tick-borne diseases in Canada. The survey can be found here: https://uoguelph.eu.qualtrics.com/jfe/form/SV_cTOKRCpZ5vVf23X?RID=MLRP_0AQ0t9Z4700jtMG&Q_CHL=email If you have any questions related to this study, please email **Cyril Akow** (cakwo@uoguelph.ca).



LYME DISEASE AWARENESS EVENT (May 2021)

With May fast approaching, we thought it would be a great opportunity to help raise awareness for Lyme disease and to let Canadians know all about the amazing work that our Network has been doing to help raise awareness, demystify and "Take a bite out of Lyme". We are still in the planning stages but wanted to reach out and see if any CLyDRN Members were interested in partnering in this virtual week of events that is slated to occur the week of **May 3rd-7th, 2021** to help kick off Lyme Disease Awareness Month. Exact dates/times are still to be determined for the various activities.

The CLyDRN Event Planning Committee welcomes suggestions (topics, speakers, activities) for the event. Your participation can be to chat about your organization and the support and resources you provide to Lyme disease patients and their families, you can present on your research findings or be a part of panel discussion on an interesting topic, you can educate on Lyme disease diagnosis, testing, treatments, and prevention or any other platform/forum is welcome. If you know of any other groups or individuals we should reach out to include to make the event a success, please let us know. Our hope is this becomes an annual event, bringing our alliances together each May for a common cause. Please reach out to the CLyDRN Network Management Office with your ideas and/or if you are interested in participating in the event.



SAVE the DATE...

Virtual 2021 MEMBERS ANNUAL GENERAL MEETING

This year's virtual AGM event is tentatively scheduled for **Wednesday, November 10th, 2021**. Agenda and registration to follow closer to the event.

If you missed out in last year's AGM (2020) the recorded video has been posted on the CLyDRN website behind the members portal. To access the video, please go to www.clydrn.ca and log into the members portal with your email/username and password. Once logged in, go to "News", then "Members Annual General Meeting". The video, including the start times for each presentation, the official program, and presentation slides have been uploaded.

WANTED: NEW MEMBERS FOR THE EVENT PLANNING COMMITTEE

The CLyDRN Event Planning Committee is looking for new members to join the committee to help with rolling out various events throughout the year (i.e., AGM, Lyme Disease Awareness Month). If any CLyDRN members are interested in joining the committee, please reach out to the CLyDRN Network Management Office.



CLyDRN Members Portal

If you have not yet created a user account on the CLyDRN website, please go to 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".

TAC Webinars

To access the Training Advisory Committee (TAC) webinars (videos and presentations), please go to 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 four videos to watch: Tick Biology and Identification 101, Patient Engagement, Tools for Bioinformatics, and Public Health Data Access and Use. Future webinars (March & April 2021) will also be posted after the presentations.

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

We will be sending out a reporting form to all our CLyDRN Members next week to help us collect some metrics about our Network. We encourage all our CLyDRN Members to take a moment to complete the form and return to the CLyDRN Network Management Office. Thank you.

CLyDRN NETWORK MANAGEMENT OFFICE

Veronica Harris-McAllister
Network Manager

E: Veronica.Harris-McAllister@kflaph.ca

T: 613-549-1232, ext. 1601 or Toll-Free:
1-800-267-7875

