



CANADIAN LYME DISEASE
RESEARCH NETWORK

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MEMBERS NEWSLETTER

MARCH 2022

Canadian Lyme Disease Research Network
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www.clydrn.ca

PILLAR UPDATES

Pillar 1

DIAGNOSTICS

The consultant continues leading the discussion between the scientific leads and patient and family partners. The research goals were presented to the Patient & Community Advisory Committee (PCAC) in January 2022 and PCAC members voted in favour of moving forward with creating a research protocol for the patient-priority project. The project will be using historical samples stored in the provincial (BC and ON) labs' freezers.

Pillar 2

PREVENTION AND RISK REDUCTION

Catherine Bouchard has replaced Patrick Leighton as one of the Co-Chairs for Pillar 2. Surveillance occurred at the sentinel sites this spring/summer 2021; analysis will begin soon on the sentinel sites' tick data. The veterinary surveillance program began as a pilot program this summer. Data analysis completed for the retrospective case-control study; in the process of writing up a manuscript. The prospective case-control study is on hold until spring 2022. The Innovation/ Intervention Working Group finalized their protocol and are currently recruiting students and trainees to help roll out the project. The Modelling working group completed a proposal for use of their seed funds; the proposal is being vetted through PCAC before it is reviewed by the CLyDRN Executive Committee for approval.

Improve prevention, diagnosis, and treatment of LD in Canada

Pillar 4

PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

Conducted 38 virtual interviews with national healthcare practitioners: 2 additional interviews scheduled for next week. Knowledge Translation Porthole discussions on hold. The focus group discussions (barriers to preventative behaviours study) have been extended into Manitoba in addition to British Columbia, Ontario, Quebec, and Nova Scotia. 22 focus group discussions have been completed to date: no longer recruiting participants. Plan to start the analysis of the focus groups at the end of March/early April. The Pan-Canadian survey will be initiated in the summer 2022; currently writing up the protocol to submit to the REB. Currently exploring funding to develop a tick bite prevention bilingual website in Quebec. Brokered dialogue protocol was finalized, and the REB application package has been completed and will be submitted after institutional signatures have been obtained. Discussions continue with the filmmaker for the brokered dialogue project. The doctoral project on Indigenous experiences and perspectives on Lyme disease continues development. The Community Engagement Committee is underway: the first two (2) community members are awaiting orientation.

Pillar 3

CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

COHORT Study-Kingston, ON Site:

*9 participants completed their Baseline visit;
8 participants completed 1-month, 3-month, and 6-month follow-up visits; 1 participant dropped out;
9-month follow-up visits are occurring over the next few weeks.*

CLYME (Biobank) Study-Kingston, ON Site:

*20 participants completed Baseline visit;
16 participants completed 1-month follow-up visit;
4 participants dropped out.*

Both studies will re-launch participant recruitment for Lyme disease cohorts and healthy controls in the coming weeks at both sites.



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@kflaph.ca.*

PCAC

PATIENT AND COMMUNITY ADVISORY COMMITTEE

There are 40 active members, including 8 members pending a new member orientation. PCAC held advisory roles by providing feedback and input through surveys and discussions with Pillar 1-4 and the Fundraising 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

FC

FUNDRAISING COMMITTEE

*Several of the Network members submitted letters of intent for the recent Public Health Agency of Canada's Infectious Disease & Climate Change grant competition. The results of the New Frontiers Research Fund (Exploration Grant) program should be announced soon; an application was submitted. FC continues to look for patient partners to join an advisory panel that will feed into various projects recently awarded funding through FC. FC also looking for Network members to join and help create and roll out new research funding applications to be able to initiative new projects. If interested in either opportunity, please reach out to **Dr. Rob Colautti** (robert.colautti@queensu.ca).*

TAC

TRAINEE ADVANCEMENT COMMITTEE

*TAC changed its name from Training Advisory Committee to Trainee Advancement Committee. TAC is in the process of reinvigorating the TAC and planning their 2022 activities. Based on the list of names of trainees sent in by supervisors, ~40-50 trainees were polled with a survey to determine an interest in webinars, organized events, and/or social networking opportunities. The first meeting of the reinvented TAC occurred on February 9, 2022. The first webinar on "Media Training" is occurring next week. If anyone is interested in presenting to TAC, please reach out to **Dr. Katie Clow** (kclow@uoguelph.ca) and **Natasha Bowser** (natasha.nofal@umontreal.ca).*



RESEARCH ARTICLES, BOOKS & INTERVIEWS

LYME CARDITIS

Article: Wamboldt R, Wang N C, Miller J C, Enriquez A, Yeung C, Chacko S, Foisy M, Baranchuk A. Pacemaker explantation in patients with Lyme carditis. JACC: Case Reports 2022 (In Press).

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.

LYME DISEASE AWARENESS EVENT (May 2022)

The CLyDRN Event Planning Committee has organized several guest speakers for our next Lyme Disease Awareness Event that will be held throughout May 2022. The event is 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*". To date we have secured 16 presenters, including 6 students and trainees. The program, including presentation dates/times will be released in the coming weeks to Network members.

We are still looking for a few additional presenters. We would also like to see more students and trainees participate in 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, you can educate on Lyme disease diagnosis, testing, treatments, and prevention or any other platform/forum is welcome. If you are interested in being a presenter, 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".

Member Annual Reporting Form

The annual reporting form was sent to all our CLyDRN Members 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 NETWORK MANAGEMENT OFFICE

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