



CANADIAN LYME DISEASE
RESEARCH NETWORK

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MEMBERS NEWSLETTER

JUNE 2020

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PILLAR UPDATES

Pillar 1

DIAGNOSTICS

The patient priorities have been identified as part of the prioritization process lead by the Patient and Community Advisory Committee (PCAC) and will soon reintegrate the scientists into these discussions as part of the next phase of activities.

Pillar 2

PREVENTION AND RISK REDUCTION

Under current COVID-19 restrictions, not able to deploy all field teams as originally planned to conduct tick surveillance this spring/summer. Working on developing data sharing agreements and will re-launch a full expanded sentinel surveillance network in 2021. Field teams out west (BC, AB, SK) can help complete some of the preparatory work this summer as they can get into the fields.

Improve prevention, diagnosis, and treatment of LD in Canada

Pillar 3

CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

The COHORT and CLYME (biobank) studies have received conditional ethical clearance to commence once COVID-19 restricted lifted. Working on obtaining ethical clearance for CASE-CONTROL study. All studies targeting participant recruitment to commence at the Kingston site late summer/early fall as part of a pilot during COVID-19 with a full re-launch to occur at both sites in 2021.

Pillar 4

PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

Grey literature review of current landscape of Lyme Disease training programs is underway. Will be submitting soon to REB the interview protocol for the national set of interviews with healthcare practitioners. The patient survey has been launched to collect feedback from patients and family members about healthcare practitioners.



COMMITTEE UPDATES

PCAC

PATIENT AND COMMUNITY ADVISORY COMMITTEE

There are 26 active members. PCAC has assisted Pillar 4 with their healthcare practitioner survey study and brokered study, assisted FC with their New Frontiers in Research Fund Letter of Intent, assisted Pillar 1 with the priority setting process and competition guidelines, and they have created a draft set of patient compensation guidelines.

CC

COMMUNICATIONS COMMITTEE

Activities currently on hold. Looking for new members to join this committee to help roll out activities.

Improve prevention, diagnosis, and treatment of LD in Canada

FC

FUNDRAISING COMMITTEE

Working on the New Frontiers in Research Fund Letter of Intent that is due mid-July.

TAC

TRAINING ADVISORY COMMITTEE

The April and May webinars were cancelled as the speakers were not available due to COVID-19 priorities. June webinar (Patient Engagement) proceeded. Both the Patient Engagement and Tick Biology & Identification 101 (January webinar) videos and presentations have been posted on CLyDRN website through the members portal.



RESEARCH PROJECTS...

Seeking Input and Participants

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_57jWsGBHBm00Kf

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



ANNUAL GENERAL MEETING (AGM 2020)

We are exploring the possibility of a half-day or full-day AGM this fall (2020) to allow CLyDRN members the opportunity to get an update from pillars and committees and to allow pillars and committees an opportunity to plan for activities in 2021. Please complete this short survey to assess your availability:

<https://www.surveymonkey.com/r/QMYFWP8>.

Depending on whether COVID-19 restrictions are still in place in 2021, we will aim for an in-person or virtual AGM next spring/summer.

WANTED: LEAD/CO-LEADS AND NEW MEMBERS FOR COMMUNICATIONS COMMITTEE

The Communications Committee is looking for new members to join the committee. The Communications Committee is also looking for a new Committee LEAD or Committee CO-LEADS to help lead the committee's activities due to the recent departure of both CO-LEADS. If any CLyDRN members are interested in joining the committee and/or becoming a LEAD/CO-LEAD, please reach out to the CLyDRN Network Management Office.

THANK YOU...

Over the past few months, we have had several CLyDRN members step back from leadership roles on various pillars and committees or within the Network Management Office. We would like to take a moment to personally acknowledge and thank them for their hard work, dedication, and commitment to CLyDRN.

Laura Bowler

Marg Cox

Donna Enright

Dan Howes

Liam Rémillard

Triant Steuart

Jason Tetro

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