Canadian Lyme Disease
Research Network

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MEMBERS NEWSLETTER

DECEMBER 2020

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

PILLAR UPDATES

Pillar 1

DIAGNOSTICS

The patient priority project has been identified by the Patient and Community Advisory Committee (PCAC). The priority project has been translated by the Pillar 1 Leads and is currently being reviewed by PCAC. The Pillar 1 scientists will be integrated in early 2021 to help develop the study design as part of the next phase of activities. Once the study design is completed, the scientists will work with PCAC on the development of the study protocol.

Pillar 2

PREVENTION AND RISK REDUCTION

Under current COVID-19 restrictions, Pillar 2 was not able to deploy field teams as originally planned to conduct tick surveillance in spring/summer 2020. The Canada Communicable Disease Report consisting of the pilot 2019 field season data was published in the October 2020 edition: **https://www.canada.ca/content/dam/phac-aspc/documents/services/reports-publications/canada-communicable-disease-report-ccdr/monthly-issue/2020-46/issue-10-oct-1-2020/ccdrv46i10a08-eng.pdf***. The retrospective case-control study is delayed starting. The prospective case-control study is on hold until spring 2021.*

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 ethical clearance and required university and hospital approvals to commence at the Kingston site. Both studies targeting participant recruitment to begin at the Kingston site in early 2021 as part of a pilot launch with a full launch to occur at both sites (Kingston, ON & Lunenburg, NS) later in 2021. Dr. Michael McDonnell is the local Lead PI at the Kingston site while Dr. Elizabeth Stringer is the local Lead PI for the Lunenburg site, replacing Dr. Todd Hatchette. Pillar 3 held their study kick-off meeting in early December 2020.

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 >160 resources have been reviewed. 10 interviews have occurred for the healthcare practitioner project. Discussions related to the knowledge translation porthole have begun. Qualitative focus group discussions are on hold until next spring/summer 2021. Brokered dialogue project is working on the REB submission with PCAC and finalizing the design of the protocol. The roll-out of this project will be on hold due to the current environment. The film study project has been postponed but groundwork is being laid with the patient stories. Community engagement project is on hold.

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 dialogue study, assisted FC with their New Frontiers in Research Fund Letter of Intent, assisted Pillar 1 with the patient priority project, and finalized the patient compensation guidelines. PCAC was also involved in creating 2 of the 3 panel discussions for the Virtual AGM 2020.

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 CLyDRN Network Management Office.

Improve prevention, diagnosis, and treatment of LD in Canada

FC

FUNDRAISING COMMITTEE

*The New Frontiers in Research Fund Letter of Intent (LOI) was submitted in July. Unfortunately, the LOI was not chosen to move forward with submitting a full application for funding. The Committee is looking for patient partners to join a new "patient advisory panel" that will be forming that will feed into the Queen's Wicked Ideas grant ($75,000) that was awarded this summer. Committee is also looking for new members to join this committee to help roll out fundraising activities. If interested in either opportunities, please reach out to **Dr. Rob Colautti** (**robert.colautti@queensu.ca**).*

TAC

TRAINING ADVISORY COMMITTEE

*Committee met in September to plan the webinars for the academic year. The Tools for Bioinformatics (November) webinar video and presentation has been posted, while the Public Health Data Access and Use (December) webinar video and presentation will be posted soon on the CLyDRN website through the members portal. Future webinars are scheduled for March and April. Committee is still looking for presenters for January and February webinars. If interested in presenting, please reach out to **Dr. Katie Clow** (**kclow@uoguelph.ca**) and **Dr. Benoit Talbot** (**benoit.talbot@uottawa.ca**).*

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_0dESA8MOywfyYM5***

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_0enCON3OGWPv7GB***

PATIENT AND FAMILY MEMBER PESPECTIVES SURVEY

*Pillar 4 is currently conducing 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_57jWsGBHBmO0KFf***

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 (Ask an Expert)

During the AGM we ran out of time to have all the questions in the chat box addressed by Dr. Adrian Baranchuk, our Keynote Speaker. We reached out to Dr. Baranchuk and here are his responses:

Q: What about non-endemic areas where patients might not be given antibiotics or Lyme tests, do you expect cardiac abnormalities to resolve or progress?

A: *Spontaneous resolution of Lyme carditis has not been documented. Unfortunately, some unexpected deaths in young individuals could be due to undiagnosed Lyme carditis. The extension of the endemic regions also brings a new challenge to physicians that do not have Lyme carditis as part of their differentials.*

Q: I'm wondering, if serological tests are so unreliable, and you have seen cases where cardiac irregularity was resolved by antibiotics, how do you reconcile the mismanagement of those patients who have Lyme Carditis but present with negative serology, through your treatment model?

A: *A very interesting (but "tricky") question. Algorithms are not intended to cover 100% of possibilities but aim to cover all of the most frequent scenarios. My feeling is that applying a systematic algorithm as the one proposed in JACC to a large series of prospective cases, it would give us the REAL sensitivity and specificity of the algorithm. Our retrospective validation lacks the precision of prospectively collected data. But this could be an international effort that may shed some light on your interesting question. For now, I prefer to say that Lyme carditis is more a clinical diagnosis than a serological diagnosis (taking into account co-infections that may respond to IV ATB with no positive serology for Lyme).*

Q: Have you looked at Lyme cases with low grade, intermittent/cyclical heart block?

A: *There are reports of low-grade AV blocks. The problem is that this "low grade AV blocks" are rarely symptomatic and patients may (or may not) have a diagnosis of Lyme diseases without investigating the heart by a simple ECG. My suggestion to investigate this further would be to do SYSTEMATIC ECG to ALL patients diagnosed with Lyme disease. This would help us detecting MORE low-grade AV Blocks.*

Q: Have you ever seen cases where the cardiac symptoms have been experienced for many years, but only recently with LC being considered?

A: *Yes. A very difficult scenario. Symptoms like palpitations, dizziness, shortness of breath, etc. could represent a large myriad of cardiovascular and non-cardiovascular diagnoses. With the available data (lack of a Long-term Lyme carditis model) is very difficult to determine whether symptoms are due to some residual Lyme carditis diseases or simply, to other causes like hypertension, diabetes, etc.*

ANNUAL GENERAL MEETING (Virtual AGM 2020)

On behalf of the AGM 2020 Planning Committee, thank you again for attending this year's virtual event held on November 4th, 2020. In total there were >120 registrants and we averaged ~75 individuals on the ZOOM call for each presentation.

The recorded AGM 2020 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 and the official program, have been uploaded. The presentation slides shown at the event will be posted in the coming weeks.

Please take a moment to complete our survey to help us collect feedback and prepare for next year's virtual AGM 2021:
https://www.surveymonkey.com/r/ZHY58YW

We are expecting the COVID-19 restrictions to still be in place in 2021 for large gatherings. We will be aiming for a virtual AGM in the Spring 2021. More details in come in the new year!

WANTED: NEW MEMBERS FOR THE AGM PLANNING COMMITTEE

The AGM Planning Committee is looking for new members to join the committee. 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.

HAPPY HOLIDAYS…

Wishing you and your families all the best over the holiday season. We hope everyone is staying healthy and safe. The CLyDRN Network Management Office will be closed on December 24th and will re-open on January 4th. Thank you for your continual support.

CLyDRN NETWORK MANAGEMENT OFFICE

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