



CANADIAN LYME DISEASE
RESEARCH NETWORK

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MEMBERS NEWSLETTER

MARCH 2020

Canadian Lyme Disease Research Network
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PILLAR UPDATES

Pillar 1

DIAGNOSTICS

Approaching the end of the patient prioritization process lead by the patient and community advisory committee and will soon reintegrate the scientists into these discussions.

Pillar 2

PREVENTION AND RISK REDUCTION

Currently working on the first publication for the Lyme sentinel network and is distributing the publication to provincial partners prior to publication. Working with Queen's and CIHR to orchestrate transfer of funds to various collaborators not identified on the initial collaborative research agreement.

Improve prevention, diagnosis, and treatment of LD in Canada

Pillar 3

CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

The cohort and biobank studies are submitting final documents to their respective research ethics boards (REBs) at McMaster and Queen's by month's end. Expect final REB clearance to commence both studies soon. Both studies are targeting recruitment to commence at the Kingston site in April in order to target the peak Lyme Disease season in the area (Jun-Aug).

Pillar 4

PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

Co-chairs will be meeting with the patient members in the coming weeks regarding the brokered dialogue. Rylan and Cécile will be presenting their final plans in preparation for the focus groups and interviews with healthcare influencers.



MONTHLY SPOTLIGHT

Each month we will highlight a CLyDRN pillar or committee. This month it's Pillar 3...

RECENT ACCOMPLISHMENTS & ONGOING ACTIVITIES

- CLyDRN has finalized the protocols and blood volumes needed for the biobank and cohort studies with the McMaster and Queen's/Kingston Health Sciences Centre teams.
- CLyDRN is considering two separate inventory management platforms to process the samples collected for the biobank and cohort studies across multiple sites for current and future Lyme Disease (LD) studies. Given that the preferred automated platform exceeds the allocated budget, network management is seeking alternate funding sources that may be available through Queen's to support the additional cost. If not successful in securing additional resources, network management will proceed as planned with the non-automated inventory system.
- CLyDRN is making progress with rolling out OSCAR (Open Source Clinical Application Resource) for the cohort and biobank studies. The inventory management system, study questionnaires, and study source documents will be embedded within OSCAR.
- CLyDRN is developing standard operating procedures (SOPs) for time of day processing of samples for the research staff at Queen's/KHSC. The SOPs will also be used for the second site in Nova Scotia (NS) once recruitment begins.

PRIORITIES & GOALS

- Approvals for ethical clearance in place for the cohort and biobank studies.
- Select the inventory management system for the studies.
- Complete dry runs for sample processing.
- Walk through the journey of a LD patient (mock dry run) at recruitment at Kingston site.
- Recruitment to commence at Kingston site for both studies.
- Activation of second recruitment site (NS).



ANNUAL GENERAL MEETING (AGM)

Considering the evolving COVID-19 situation we are all facing together, CLyDRN Executive Committee has decided to postpone the AGM until the Fall 2020. We had hoped to proceed with a virtual-only AGM on May 14th but given that many of our CLyDRN Members are being pulled away to deal with COVID-19 priorities, we have decided to cancel the virtual AGM. We will continue to assess the environment and we hope to proceed with the AGM this fall. The agenda will be circulated closer to the AGM.

COVID-19

The rapidly evolving situation associated with COVID-19 has led to numerous discussions regarding research activities across university, hospital and research institutions across the country. CLyDRN Network Management Office supports the continuation of research activities recognizing that the health and well-being of the research community, its patients/participants, and the general community is of paramount importance. We recognize our CLyDRN members, especially those in the public health, hospitals, community centres and beyond, are being pulled away to track and manage the evolving COVID-19 situation in Canada. We understand that our CLyDRN members are assessing the environment and looking into back-up plans and exploring options to enable research activities under CLyDRN to continue. We thank you for your continual support. If you have any concerns related to your ability to complete CLyDRN pillar and/or committee work, please reach out to Liam and Veronica (see contact information to the right).

PILLAR/COMMITTEE LEADS: *we need to hear from you...*

We are preparing a briefing note to submit to CIHR to identify how COVID-19 is influencing CLyDRN and our ability to meet our milestones and deliverables outlined under each pillar and committee. Many of the pillars/committees will need to adapt considering travel restrictions and social distancing measures are in place and will need to look into back-up plans and explore options to enable research activities under CLyDRN to continue. We need the leads/co-chairs of each pillar/committee to provide a brief written summary of the impact and modifications to their CLyDRN work due to COVID-19. We will also be confirming with CIHR our reporting deadlines related to our annual report due this spring.

Please send all summary reports to Liam and Veronica (see contact information below) ***no later than March 31st***.

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