



# CANADIAN LYME DISEASE RESEARCH NETWORK

## QUARTERLY NEWSLETTER

### Introduction

Over the past year, significant accomplishments have been made towards establishing the research network and initiating components of the research portfolio. Acting on recommendations from CIHR, the network governance was revised by amalgamating the responsibilities of several advisory committees. Each of the four research pillars, and five of the advisory committees have been populated with drafted terms of reference. While the executive committee meets bi-weekly to discuss pertinent matters related to network operations, all other committees and Pillars have been meeting from bi-weekly to quarterly. All Pillars, committees, and stakeholders were invited to participate in our Annual General Meeting (AGM) held in Ottawa on April 3rd, 2019. The AGM served as a project kickoff and provided an opportunity for each of the Pillars/committees to discuss future plans and strategize how our network should address the five mission critical CIHR requirements. Our second AGM will be held May 14th-15th at KFL&A Public Health in Kingston, Ontario, so book your rooms now at the Donald Gordon Conference Centre. A draft agenda has been developed and will be distributed in the new year.

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### Pillar 1 Update

#### DIAGNOSTICS

We have reorganized the structure of the pillar so that Network diagnostics research will be conducted explicitly in response to patient-identified research priorities. The committee terms of reference have been ratified, and we are working in partnership with patient engagement researchers and the Patient and Community Member Advisory Committee to establish a robust process for identifying and prioritizing patient and community research priorities. We expect that this prioritization process will take ~6 months, but will not have samples with which to work for at least 1 year.

### Pillar 2 Update

#### PREVENTION AND RISK REDUCTION

Working groups have been established to oversee Pillar 2 activities in 4 main areas: Surveillance, Epidemiology, Risk Reduction Innovation, and Modelling. The study protocol has been developed and paperwork completed for data linkage at ICES for the retrospective case-control study. Sentinel surveillance for 2019 was completed in all sentinel regions and analysis has begun. Preliminary results of the analyses will be shared with the network in 2020.

## Pillar 3 Update

### CLINICAL SCIENCE AND HEALTH SERVICES RESEARCH

There has been significant progress made on the design update and plans for implementation of the cohort study. This longitudinal study was re-designed in order to meet both scientific needs and the needs of stakeholder groups. This includes the establishment of a standard cohort of patients with Lyme Disease who are in various stages of the illness. We also will enroll a second cohort of patients who meet clinical criteria but do not meet CDC laboratory diagnostic criteria. Detailed physical and cognitive assessments will be captured along with broad immunological testing.

## Cohort Study Update

#### Protocols

Clinical protocols for all four cohorts have been revised with patient input. The clinical cohort will follow four groups forward in time. The primary group will include adults with untreated, confirmed cases of Lyme Disease (LD) (i.e., early localized, early disseminated, and late disseminated). A hypothesis-generating LD group will include patients that present with flu-like symptoms who test positive for LD. Additionally, a secondary LD group will be created to include patients who meet clinical criteria for early or late disseminated LD but who do not meet CDC criteria. A control group will be followed at the same time points as the other cohorts. This group will serve as a comparison group for diagnostic testing, immunological testing, and LD risk factor assessment. These protocols have received ethics approval from McMaster's Research Ethics Board, and will be submitted to Queen's Research Ethics Board in early 2020. We hope to receive approval from Queen's before recruitment begins in Q1 2020.

#### Staffing and Logistics

Research staff, including research coordinators, research assistants, phlebotomists, and technicians have been hired at Kingston sites. Electronic medical records and inventory management IT infrastructure are in development. They are scheduled to be ready before recruitment begins in Q1 2020.

#### Recruitment

Initial recruitment of 50 patients for the cohort study will begin in Q1 2020 at the two Kingston sites (i.e., Kingston General Hospital and Hotel Dieu). Lessons learned from this process will be formalized before recruitment begins at our second site in Lunenburg, Nova Scotia. This is scheduled to begin in Q2 of 2020.

## Pillar 4 Update

### PATIENT AND COMMUNITY ENGAGEMENT, TRAINING, AND KT

We have had an inaugural Pillar meeting, confirmed Pillar 4 membership and ratified the committee terms of reference. We have developed research protocols and initiated working groups of Pillar 4 members interested in contributing to the initial qualitative studies planned. We have also drafted an approach to evaluating our Pillar that is aligned with the Network as a whole.

## Patient Engagement Update

Given our patient-oriented framework, the Network has been working on developing a governance structure that includes different stakeholders. This has required the creation and definition of new roles for patients as well as the development of a process to facilitate the inclusion, dialogue, and consensus-building among all members of the Network. As an example of actions taken, all four Pillars have been structured to include two co-chairs (one scientist and one patient), with the goal of eventually having 50% patient representation across all Pillars. This is still a work-in-progress and it is being implemented in partnership with patients, scientists, and clinicians. As part of this engagement work, all pillars are continuing to refine their research priorities and governance structures in alignment with the CIHR SPOR guidelines; for example, the Network is developing a process to incorporate the results of the priority setting into the work of the pillars, a process which is led by the Patient and Community Advisory Committee.

Additionally, the Network initiated a process to engage and partner with patients with LD across Canada. This process consists of: 1) establishing connections with patients from the different provinces and territories and, 2) building relationships between scientists and patients in the Network. This work has proved challenging, due in part to the controversies that characterize the LD research landscape in Canada and the Network's limited experience and skills with respects to engagement at the outset. Our engagement strategy has evolved considerably and is focused on building an organizational structure that guarantees a process to incorporate the varied perspectives within the Network.

## Knowledge Advancement

- Novel Research Method
  - We have developed a clinical protocol for the cohort study that will be conducted by CLyDRN to describe patterns of physical and mental outcomes of LD, and to assess predictors of long-term outcomes and factors associated with delayed recovery. The protocol describes methods and measurement indicators to capture patient-relevant outcomes.
- Novel Database
  - We have developed a unique form of OSCAR (Open Source Clinical Application Resource) that will allow all data from the cohort study to be collected and stored there, including questionnaires, lab results and biobank specimen counts to be stored at the centre for advanced computing at Queen's University. This also allows clinical data to be linked to the biobank samples.
- 2 Guidelines for Policy and Practice currently under development

## Knowledge Dissemination

- 15 Invited Presentations, including:
  - Public Health Agency of Canada's Multidisciplinary Meeting on Lyme Disease
  - Public Health Physicians of Canada Webinar
  - Ottawa Kingston Microbiology Infectious Disease Meeting
  - 2 Queen's University CPD Events entitled "Acute Lyme Disease: Diagnosis, Treatment and New Research Initiatives"
- Media Interactions
  - Global News: Kingston Chief Medical Officer Involved in \$4M Lyme Disease Research Project
  - CBC: Kingston Doctor Leading Fight Against Lyme Disease
  - Queen's Gazette: Queen's Receives \$4M for New Lyme Disease Research Network
  - Kingston Whig Standard: Queen's University to Lead Research into Lyme Disease

## Network Manager Report: Liam Rémillard

This network has witnessed a tremendous amount of growth and evolution over the past year. Major milestones include: building patient and professional relationships, assembling research pillars and advisory committees, developing project management plans, conducting our inaugural annual general meeting, revising clinical cohort protocols, developing the clinical data management repository, signing the collaborative research agreement, and transferring funds to partner institutions. Some timelines needed to be adjusted to accommodate unanticipated administrative delays associated with the collaborative research agreement, and we appreciate everyone's patience as we navigated this process and apologize for any inconvenience this may have caused. The major upcoming milestone for Q1 of 2020 we are working towards involves acquiring ethics clearance, training staff, and finalizing the inventory management system to facilitate the pilot of the clinical cohort in Kingston.

Lastly, I would like to inform the network members that I have given my formal notice of resignation and will be stepping down from my position as the network manager as of April 30th, 2020.

Queen's has hired Veronica Harris-McAllister ([veronica.harris-mcallister@kingstonhsc.ca](mailto:veronica.harris-mcallister@kingstonhsc.ca)) to fill the role of the network manager and I will ensure that Veronica is trained on the roles and responsibilities of this position prior to my departure. Prior to joining CLyDRN, Veronica Harris-McAllister was the Director of Health Sciences Research at the Kingston General Health Research Institute. Previously she held the role of Manager of Health Sciences Research at the Research Institute (2008-2017). Ms. Harris-McAllister has over 20 years of experience working in clinical, pharmaceutical, and administrative research. She worked in the Respiratory Investigation Unit at Queen's University (2004-2008) and at the University of Ottawa Heart Institute in the Prevention and Rehabilitation Centre (2001-2004). Ms. Harris-McAllister is a graduate of Queen's University (BSc, Biochemistry), University of New Brunswick (BPHE, Sports Science), and East Stroudsburg University (MSc, Cardiac Rehabilitation & Exercise Sciences).

It has been a pleasure and a privilege serving this network over the past year, and I have the fullest of confidence that the incoming network manager and senior leadership will maintain progress in 2020.

## Trainee Webinar Series

The Training Advisory Committee is in the process of developing a WebEX-style webinar series for CLyDRN trainees. The intended purpose of this webinar series is to provide trainees the opportunity to learn about various topics related to Lyme Disease research. Each webinar will be recorded and available on the website for viewing among all CLyDRN members.

## Website Update

The appearance and content of the website is in the process of being redeveloped by web designers at KFL&A Public Health. This website redesign will allow members to readily access newly posted information and also view a calendar for upcoming events. Further modifications to the website will be conducted in collaboration with the patient and community advisory committee and the TechnicalitiesPlus design team. All website revisions are intended to be finalized in Q1 2020.

## Upcoming Milestones

The first milestone will be for all partner institutions to receive year one funds. While some partners have been operating on reserve funds, timely dissemination of these funds will be necessary for all future Pillar activities. The second milestones will be the commencement of recruitment for the clinical cohort pilot in Kingston, then proceeding to add the Nova Scotia recruitment site.

