



CANADIAN LYME DISEASE RESEARCH NETWORK

A YEAR IN REVIEW

333 Members

50 Patient Partners

21 CLyDRN Webinars

52 Publications

1 Books & Book Chapters

2 Reports & Technical Reports

79 Presentations

70 Interviews

162 Students & Trainees

\$1.47M New Funding

247 Stakeholders involved in various stages of Research Process

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Message from the Director

As we move beyond the initial phase of our research network, we look forward to exciting years ahead focused on turning the visioning and strategic planning carried out over the past two years into new research opportunities and partnerships, positioning the network to address the broader challenges of climate-driven emergence of a broad range of tick-borne diseases in Canada.

Our research network draws strength from its diversity, bringing together patients, family caregivers, community partners, healthcare professionals, and other stakeholders in addition to researchers, students, and trainees, all of whom have contributed to propelling the network to where it is today and shaping the vision for the future. Some notable accomplishments of our network over the past year include:

- 1) The Lyme disease awareness events held in May 2023 and the 2022 CLyDRN Annual General Meeting (AGM) held in November 2022 were very successful, featuring presentations from stakeholders across the country including researchers, students, trainees, patients, family caregivers, community members, and Lyme advocates who all volunteered time to participate.
- 2) The emergence of a broadened vision and scientific focus to consider the other tick-borne diseases presenting new challenges across the Canadian landscape and evolve the research network to expand beyond Lyme disease and its vectors to include other ticks and tick-borne diseases (TickNet Canada; <https://ticknet.ca/>).
- 3) Securing extension funding from CIHR to maintain the network's activities as we transition from CLyDRN to TickNet Canada.
- 4) Making decisive progress toward the completion of each of the Pillar research projects, including continued recruitment into the COHORT, CLYME-Biobank and prospective case control studies, launch of the Brokered Dialogue project, pan-Canadian survey, TickTOOL webplatform, and the Pillar 1 project, and ongoing expansion of our Sentinel Surveillance Program (CaLSeN) which has doubled since its launch in 2019 and now includes almost 200 sites across 36 sentinel regions in 2023.



- 5) Continued focus on translating priorities identified by our patients, family caregivers, and community stakeholders through engagement and collaboration into fundable new research directions as we plan for the future.

We look forward to seeing many of you at our inaugural TickNet Canada Scientific Symposium in Toronto, ON (October 24-25, 2023), and our associated 2023 CLyDRN AGM that will provide a high-level overview of our pillar and committee activities over the past year and progress toward launching the next phase of the network. The following pages provide a written summary of CLyDRN's research and training activities over the past year.

We cannot thank you enough for your ongoing support of our network and look forward to welcoming you at our virtual and in-person events in the coming year.



Patrick Leighton, BSc, PhD

Professor of Epidemiology & Public Health, Faculty of Veterinary Medicine, Université de Montréal
Director, Canadian Lyme Disease Research Network (CLyDRN)



Pillar and Committee Updates

Pillar 1 (Diagnostics)

(CO-LEADS: *Twylla Bird-Gayson, Muhammad Morshed & Terrie Wainwright*)

It has been an exciting year for Pillar 1 as the study proposal was completed by late fall 2022, and Patient and Community Advisory Committee (PCAC) members voted unanimously to support the proposal moving forward. The proposal was awarded seed funding from the CLyDRN Executive Committee. Research Ethics Board (REB) applications were submitted and received approval (after seven rounds of revisions) by the University of British Columbia, and both provincial labs in the spring 2023, all accomplished after nine months of preparation led by Pillar 1 members and our consultant.

Due to the delay in obtaining ethics clearance, we were unable to roll out the prospective serum samples collection from new patients (first tick bite/exposure) who are being serologically tested for Lyme disease during the 2023 Lyme disease season from the provincial labs in British Columbia (British Columbia Centre for Disease Control Public Health Laboratory) and Ontario (Public Health Ontario Laboratory in Toronto). The provincial labs will instead begin collecting prospective samples in the spring 2024. Since the provincial labs in British Columbia and Ontario have all their resources in place, a decision was made to proceed with the analysis of retrospective samples currently stored in the provincial labs in British Columbia and Ontario. To minimize inter-laboratory variation all study samples (retrospective and prospective) will be analysed in the British Columbia provincial lab for enzyme immunoassay (EIA), and Western Blots (WB) will be done at National Microbiology Laboratory. As a result of these delays, data analysis of the samples will occur later in 2024 or early 2025.

Pillar 1 researchers and patient partners have also been selected to pilot the implementation of *Guidance for Reporting Involvement of Patients and the Public* version 2 short form (GRIPP2-SF) checklist, using the current research study, to recognize contributions made by all Pillar 1 and PCAC members. The Pilot Project includes patient partners throughout the research process by involving them in the development of the research protocol, monitoring the study's progress, reviewing the results, and writing the manuscript/publications, and other knowledge translation activities. A Ph.D. student from the University of Toronto will be hired in the coming months to facilitate the researchers' and patient partners' contributions to this project deliverable.



Pillar 2 (Prevention & Risk Reduction)

(CO-LEADS: Catherine Bouchard, Manisha Kulkarni & Pamela Scott-Crace)

Pillar 2 aims to assess, track, and predict the changing risk of Lyme disease in Canada to identify and inform targets for risk reduction through three project initiatives:

- **Canadian Lyme Sentinel Network (CaLSeN)**: The Canadian Lyme Sentinel Network is a pan-Canadian network of sentinel regions providing the necessary data to support studies aimed at understanding and predicting Lyme disease risk for Canadians from coast to coast.
- **Longitudinal Risk Study**: The Longitudinal Risk Study is a multi-site longitudinal study built on the sentinel network structure, making it possible to assess the effects of environmental, social, and individual determinants on emerging Lyme disease risk across Canada.
- **Risk Reduction Innovation Program**: The Risk Reduction Innovation Program uses seed funding to stimulate innovative research into new ways to measure, map and reduce Lyme disease risk in Canada. Research directions are developed by two dedicated think tanks (interdisciplinary working groups) bringing together researchers, patients, and stakeholders from a diversity of sectors across Canada, with proposals reviewed at the network level.

Four working groups were established to oversee the three Pillar 2 project initiatives: Surveillance, Epidemiology, Intervention, and Modelling. Pillar 2 presented an update on all Pillar 2 working group activities at the CLyDRN AGM in November 2022 and held a Pillar-wide meeting in May 2023 to provide further updates to Pillar 2 members. A summary of the objectives and progress of each working group follows:

Surveillance Working Group

The objective of the Surveillance Working Group is to develop a pan-Canadian network of sentinel regions where active tick surveillance is conducted on an annual basis to assess the status of *Ixodes scapularis* (*I. scapularis*) populations and the accompanying pathogens. Field surveillance data will be integrated with other surveillance data to provide a comprehensive picture of Lyme disease risk across these sentinel regions.



The network (CaLSeN) was established in 2019, with at least one sentinel region in each province. It has subsequently expanded and with additional funding from the Public Health Agency of Canada, our field surveillance effort has doubled from 2019 to include almost 200 sites across 36 sentinel regions in the 2022-23 field season (see list of sentinel regions below). Funding from PHAC and the CIHR extension grant will enable annual surveillance activities to be extended beyond 2023 to collect multiple consecutive years of data.

Research Questions:

- 1) What is the current distribution of *Ixodes scapularis* and its pathogens across selected regions in Canada? How does this change over time?
- 2) What is the value of integrating veterinary tick and tick-borne disease data into the sentinel surveillance approach? How can this be done effectively and efficiently?

Expected outcomes:

We will generate a longitudinal dataset that illustrates the status of *I. scapularis* populations in regions across Canada, as well as the infection prevalence of pathogens of human and animal health concern within these populations, including *Borrelia burgdorferi* (*B. burgdorferi*). We will generate maps each year depicting the surveillance findings of each sentinel region. A shared dataset will be available to all collaborators.

2022-23 Activities:

In 2022-23, this group conducted CaLSeN tick surveillance activities in spring/summer 2023 in collaboration with provincial and regional public health partners in all sentinel regions. Teams from Université de Montréal, University of Ottawa, University of Guelph, University of Manitoba, University of Saskatchewan, British Columbia Centre for Disease Control (BCCDC), University of New Brunswick, Centre for Coastal Health (British Columbia), University of Calgary (Alberta) and Acadia University (Nova Scotia) participated in field surveillance in their respective provinces.



In 2023 there was active tick surveillance 197 sites in 36 sentinel regions; *Ixodes scapularis* was detected in 17 regions in 2023. Laboratory testing of collected tick specimens during the spring/summer 2023 will be completed in Sept-Dec 2023 and data will be compiled for results synthesis.

Analysis of results is ongoing from a pilot study that was launched in 2021-22 to examine the utility of integrating veterinary tick and tick-borne disease data into the sentinel network. Sixteen clinics across four sentinel regions in Ontario are part of this pilot project.

The sentinel regions of CaLSeN are as follows:

- British Columbia (BC): Victoria, Vancouver, North Vancouver Island, Okanagan
- Alberta (AB): Lethbridge, Red Deer, Calgary, Edmonton
- Saskatchewan (SK): Regina, Saskatoon, Yorkton/Russell* (three sites in SK), +/- Prince Albert
- Manitoba (MB): Winnipeg, Brandon, Yorkton/Russell* (two sites in MB)
- Ontario (ON): Sault Ste. Marie, Sudbury, Kingston, Ottawa-Gatineau, Peterborough, Muskoka, London, Guelph +/- Kenora
- Québec (QC): Montréal, Trois-Rivières, Sherbrooke, Québec, Saguenay, Rivière-du-Loup
- New Brunswick (NB): Fredericton, Saint John
- Nova Scotia (NS): Digby, Lunenburg, Amherst
- Prince Edward Island (PEI): Charlottetown
- Newfoundland & Labrador (NFLD): St. John's, Corner Brook

The sentinel regions in Ontario in which the veterinary sentinel surveillance pilot is being conducted are Guelph, Ottawa, Kingston, and Muskoka.

Epidemiology Working Group

In the Canadian context, many individual, environmental, and socioeconomic risk factors for human Lyme disease infection are yet to be ascertained. To address this knowledge gap, this working group oversees the Longitudinal Risk Study, which is comprised of two activities: (1) retrospective case-control study, and (2) prospective case-control study. The objective of the Longitudinal Risk Study is to identify and estimate the significant determinants of Lyme disease risk, including the degree of risk associated with residential and community exposure to ticks, and to assess differences knowledge, attitudes, and



practice (KAP) related to Lyme disease. We will also assess how Lyme disease risk, its determinants, and KAP differ between endemic sites in ON and NS.

The retrospective case control study is a matched case-control study focusing on southeastern Ontario, using Lyme disease patient data from provincial laboratory databases and uninfected population controls accrued from 2014-2018. The prospective case control study is being conducted in two sites (Kingston, ON and Lunenburg, NS), using cases from the Pillar 3 COHORT study and hospital-based controls.

2022-23 Activities:

In 2022-23, results of the retrospective case-control study were published in December 2022 (<https://www.liebertpub.com/doi/10.1089/vbz.2022.0044>) in *Vector-borne and Zoonotic Diseases*. The manuscript, titled "*Rurality, socioeconomic status, and residence in environmental risk areas associated with increased Lyme disease incidence in Ontario, Canada: A case-control study*" found that living in an area with high environmental risk (high predicted tick occurrence) (odds ratio (OR)=2.4; 95% confidence intervals (CI)=2.2, 2.6), low walkability (OR=4.1; CI=3.2, 5.3) and transit scores (OR=2.9; CI=2.2, 3.8), high proportion of parks (OR=1.034; CI=1.031, 1.036), and increased length of trail networks (OR=1.020; CI=1.010, 1.027) were significant neighbourhood risk factors for Lyme disease as well as higher neighbourhood socioeconomic status (high neighbourhood income: OR=2.1; CI=1.8, 2.4; low material deprivation: OR=2.3; CI=1.9, 2.7; low ethnic concentration: OR=12.8; CI=10.7, 15.3). Using multivariable modelling to adjust for these neighbourhood and socioeconomic risk factors, we found that the odds of Lyme disease infection for individuals residing in environmental risk areas was highest for those living in public health units with <250,000 population (OR=2.3; CI=1.7, 3.0) compared to those living in public health units with >1,000,000 population (OR=1.4; CI=0.97, 2.0). This study demonstrated that risk of human Lyme disease infection in Ontario, Canada is higher in less urbanized areas with higher socioeconomic indices and affirms that living in regions with higher occurrence of ticks in the environment is linked to increased odds of tick-borne diseases. Final results of this study were presented at the November 2022 AGM.

For the prospective case-control study, which was delayed due to COVID-19 disruptions alongside the Pillar 3 COHORT study, the study was launched at the Kingston (ON) site in the spring/summer 2022 alongside the Pillar 3 COHORT study participant recruitment, while recruitment was launched in Lunenburg (NS) in spring/summer 2023. Recruitment continued until early 2023 in Kingston and is ongoing in Lunenburg. The study is collecting information on KAP regarding Lyme disease and exposure to Lyme disease risk



areas from 90 Lyme disease cases (i.e., the early localized Lyme disease and early disseminated Lyme disease cases recruited through the COHORT study) and 180 matched controls using a structured questionnaire. The expected outcomes of this study include better understanding of the risk factors for Lyme disease infection and improved understanding of KAP differences between those with Lyme disease and those without, that can be used by our public health partners to inform Lyme disease campaigns. Project outputs will include scientific publications and presentation(s) and a policy brief.

Intervention Working Group

This group has oversight of the “risk reduction interventions” component of the Risk Reduction Innovation Program, which aims to:

- 1) Identify the most promising research topics for reducing Lyme disease risk across Canada.
- 2) Engage in continuous scientific monitoring, knowledge sharing about the new intervention/mitigation strategies (from the working group to the CLyDRN) and facilitating their implementation in Canada.
- 3) Develop guidelines to evaluate tick and Lyme disease intervention/mitigation strategies including (1) the potential public health impact of the existing or novel approaches; and (2) obstacles and levers to the implementation of these interventions.

In 2022-23, the working group has worked on projects focusing on the prioritization and assessment of Lyme disease interventions (i.e., systematic review, cost-efficacy modeling, and MCDA for rodent-targeted interventions), which was developed in consultation with the PCAC members and approved by the CLyDRN Executive Committee. The project activities started in Winter 2022.

Current projects involve:

- 1) Reviewing and assessing available preventive interventions relevant to the Canadian context (Status: ongoing - expected ending: June 2023) (Katarina Ost, University of Ottawa). WG objectives 1 & 2



- 2) Modeling the cost-efficacy of various rodent-targeted interventions (Status: beginning in June 2022 - expected ending: June 2025). WG objective 3.1
- 3) Prioritizing rodent-targeted interventions through an updated Multicriteria decision analysis process based on stakeholder consultations (Status: beginning in August 2022 - expected ending: June 2024) (Ariane Dumas & H el ena Ladreyt, Universit e de Montr eal). WG objective 3.1
- 4) Healthy cities initiatives (CIHR funds – Universit e de Montr eal & University of Ottawa): Planning and developing Canadian intersectoral partnerships and knowledge sharing for sustainable LD risk mitigation in peri-domestic high-risk areas (Status: beginning in January 2023- expected ending: June 2024). (Camille Guillot, Universit e de Montr eal). WG objective 2

The Intervention Working Group also received a CIHR grant for the Healthy cities project, that aimed at:

- 1) Developing a Canadian mapping of municipal stakeholders, researchers, citizens, and private businesses willing to get involved in collaborative development and implementation Lyme disease risk reduction interventions.
- 2) Conducting an environmental scan to identify Lyme disease high risk areas with significant at-risk populations where Lyme disease interventions have a potential for being adequately implemented, locally managed, and evaluated by collaborative efforts of the research team and local stakeholders.
- 3) Sharing scientific knowledge and local experience and identify key components of Lyme disease risk reduction integrated interventions that could be applied and evaluated in each municipality’s specific context during a two-day workshop with citizens, municipal stakeholders, and researchers.

Modelling Working Group

This group has oversight of the “modelling and mapping” component of the Risk Reduction Innovation Program. The objectives of the group are to facilitate modelling to support public health policies and programs directly, and to develop hypotheses on factors determining transmission of tick-borne pathogens. including modelling current spatial occurrence, spatial spread, and impacts of interventions. The group also aims to



facilitate modelling of the ecology of tick-borne disease to develop hypotheses on environmental determinants of transmission, the transmission dynamics of different strains, and impacts of climate and other environmental/land use/socio-economic changes.

Expected outcomes:

Increased understanding of tick-borne disease transmission to support public health policies and programs including understanding current spatial occurrence, spatial spread, and impacts of interventions.

2022-23 Activities:

While most work was delayed due to COVID-19, CLyDRN-related work on modelling of spatial spread of *I. scapularis* and tick-borne agents continued at Université de Montréal. Mechanistic movement models and agent-based modelling of Lyme disease dispersion have been developed and implemented in 2022-2023, with two articles published in 2022-2023 (Tardy et al. 2022; Tardy et al. 2023).

In 2022 the working group received a seed grant for the project for the development of models of Lyme disease risk, which was submitted to the network for review in the Winter 2022. The project was developed in consultation with the PCAC members and was recently approved by the CLyDRN Executive Committee. The project activities started in the summer of 2022.

The main research objectives of the project are to:

- 1) Facilitate modelling to support public health policies and programs:
 - a. modelling current spatial occurrence,
 - b. spatial spread, and
 - c. impacts of interventions

- 2) Facilitate modelling of the ecology of tick-borne disease to develop hypotheses on environmental determinants of transmission:
 - a. transmission dynamics of different strains, and
 - b. impacts of climate change
 - c. and other environmental/land use/socio-economic changes.



Pillar 3 (Clinical Science & Health Service Research)

(CO-LEADS: Twylla Bird-Gayson, Rob Brison, Mark Loeb, Beate Sander, Elizabeth Stringer & Terrie Wainwright)

Pillar 3 has two main projects: the COHORT study and CLYME (Biobank) study. Pillar 3 also carries out participant recruitment and data collection (Baseline visit only) for the Pillar 2 prospective case-control study. There are two recruitment sites: Lunenburg, NS, and Kingston, ON.

The COHORT study examines the longitudinal health and economic impact of Lyme disease, identifies predictors of recovery, and will lay the foundation for future Lyme disease research in Canada. Various Lyme disease and healthy control participants will be recruited into the study and include: (1) patients with confirmed Lyme disease (symptoms of Lyme disease and Lyme serology test is positive), these would be your early localized, early disseminated, and late disseminated Lyme disease cases; (2) the Hypothesis Generating-Comparison Group, which includes patients with flu-like illness but without your typical Lyme disease rash and the Lyme serology test is positive; (3) Secondary Cohort-Comparison Group, which includes clinical symptoms of Lyme disease and the Lyme serology test result is negative; and (4) your healthy controls. Study participants are then followed at Baseline, 1 month, 3 months, 6 months, 9 months, 12 months, and 24 months. The 24-month follow-up is only completed by participants enrolled in the COHORT study before February 6, 2023. The CLYME (Biobank) study was created to collect and store specimens (blood, urine, other fluids) and clinical data for future Lyme disease research projects. Culturing *Borrelia* from human samples (blood and tissue biopsy) is also occurring for this study. Lyme disease patients and healthy controls will be recruited. The Lyme disease patients are not stratified as mentioned in the COHORT study.

Pillar 3 members (scientists, research team members, and patient partners) continued to meet monthly over the past year. As a result of the discussions and evaluation of recruitment during the past two Lyme disease seasons, staffing was enhanced at the Lunenburg, NS, site in preparation for the 2023 Lyme disease season. Participant recruitment recommenced in April 2023 at the Lunenburg, NS site for the CLYME (Biobank), COHORT, and prospective case-control studies. The Kingston site only carried out participant follow-up for the COHORT study for Lyme disease and healthy control participants recruited into the study during the 2021 and 2022 Lyme disease seasons. The Kingston, ON, site is no longer actively recruiting new participants for the three studies. The first cohort of Lyme disease participants (N=8) recruited into the COHORT study in



the 2021 Lyme disease season completed their 24-month follow-up visit in August 2023, with just one participant not completing the 24-month follow-up assessment (lost to follow-up).

The total number of participants enrolled in all three studies during the 2021, 2022, and 2023 Lyme disease seasons for both recruitment sites can be found below:

CLYME (Biobank) Study:

| | Lyme disease cases (Target = 200) | | | Healthy controls (Target = 200) | | |
|---|-----------------------------------|-----------|-----------|---------------------------------|-----------|-----------|
| | Kingston | Lunenburg | TOTAL | Kingston | Lunenburg | TOTAL |
| Participants had been enrolled (consented) into the study | 62 | 8 | 70 | 2 | 37 | 39 |
| Participants completed the Baseline study visit | 59 | 8 | 67 | 2 | 37 | 39 |
| Participants completed the 1-month study visit | 52 | 3 | 55 | 2 | 35 | 37 |
| Participants withdrew from further participation | 4 | 0 | 4 | 0 | 0 | 0 |
| Participants lost in follow up | 16 | 0 | 16 | 0 | 0 | 0 |
| Participants refused to participate | 52 | 9 | 61 | 70 | 0 | 70 |

COHORT Study:

| | Lyme disease cases (Target = 210) | | | Healthy controls (Target = 30) | | |
|---|-----------------------------------|-----------|-----------|--------------------------------|-----------|-----------|
| | Kingston | Lunenburg | TOTAL | Kingston | Lunenburg | TOTAL |
| Participants had been enrolled (consented) into the study | 36 | 6 | 42 | 2 | 29 | 31 |
| Participants completed the Baseline study visit | 30 | 6 | 36 | 2 | 29 | 31 |
| Participants completed the 1-month study visit | 28 | 2 | 30 | 2 | 29 | 31 |
| Participants completed the 3-month study visit | 27 | 1 | 28 | 2 | 25 | 27 |
| Participants completed the 6-month study visit | 25 | 1 | 26 | 2 | 15 | 17 |
| Participants completed the 9-month study visit | 24 | 1 | 25 | 2 | 7 | 9 |
| Participants completed the 12-month study visit | 21 | 0 | 21 | 0 | 0 | 0 |
| Participants completed the 24-month study visit | 7 | 0 | 7 | 0 | 0 | 0 |
| Participants withdrew from further participation | 1 | 0 | 1 | 0 | 0 | 0 |
| Participants lost in follow up | 9 | 0 | 9 | 0 | 0 | 0 |
| Participants refused to participate | 71 | 9 | 80 | 70 | 0 | 70 |

| | Breakdown of Lyme disease case and healthy controls | | | Study Target Overall Numbers |
|---|---|-----------|-----------|------------------------------|
| | Kingston | Lunenburg | TOTAL | TOTAL |
| Group A, early localized Lyme disease | 27 | 6 | 33 | 60 |
| Group A, early disseminated Lyme disease | 0 | 0 | 0 | 30 |
| Group A, late disseminated Lyme disease | 0 | 0 | 0 | 30 |
| Group B, early localized, hypothesis-generating | 4 | 0 | 4 | 30 |
| Group C, early disseminated Lyme disease | 0 | 0 | 0 | 60 |
| Group C, late disseminated Lyme disease | 0 | 0 | 0 | |
| Group D, healthy controls | 2 | 29 | 31 | 30 |



Prospective Case-Control Study (Pillar 2):

| | Healthy controls recruited in COHORT Study | | | Healthy controls recruited in Prospective Case-Control Study | | | Healthy controls recruited in CLYME-Biobank Study | | | Study Target Overall Numbers (Target = 180) |
|---|--|-----------|-------|--|-----------|-------|---|-----------|-------|---|
| | Kingston | Lunenburg | TOTAL | Kingston | Lunenburg | TOTAL | Kingston | Lunenburg | TOTAL | COMBINED TOTALS |
| Participants had been enrolled (consented) into the study | 2 | 29 | 31 | 45 | 23 | 68 | 2 | 20 | 22 | 121 |
| Participants completed the Baseline study visit | 2 | 29 | 31 | 45 | 23 | 68 | 2 | 20 | 22 | 121 |
| Participants withdrew from further participation | 0 | 0 | 0 | 0 | 0 | 0 | | | | |
| Participants lost in follow up | 0 | 0 | 0 | 0 | 0 | 0 | | | | |
| Participants refused to participate | 70 | 0 | 70 | 24 | 0 | 24 | | | | |

| | Lyme disease cases recruited in COHORT Study | | | Lyme disease cases recruited in Prospective Case-Control Study | | | Study Target Overall Numbers (Target = 90) |
|---|--|-----------|-------|--|-----------|-------|--|
| | Kingston | Lunenburg | TOTAL | Kingston | Lunenburg | TOTAL | COMBINED TOTALS |
| Participants had been enrolled (consented) into the study | 36 | 6 | 42 | 0 | 29 | 29 | 71 |
| Participants completed the Baseline study visit | 30 | 6 | 36 | 0 | 29 | 29 | 65 |
| Participants withdrew from further participation | 1 | 0 | 1 | 0 | 0 | 0 | |
| Participants lost in follow up | 9 | 0 | 9 | 0 | 0 | 0 | |
| Participants refused to participate | 71 | 9 | 80 | 0 | 9 | 9 | |

| | Breakdown of Lyme disease cases in COHORT Study | | | Breakdown of Lyme disease cases in Prospective Case-Control Study | | | Study Target Overall Numbers (Target = 90) |
|--|---|-----------|-------|---|-----------|-------|--|
| | Kingston | Lunenburg | TOTAL | Kingston | Lunenburg | TOTAL | COMBINED TOTAL |
| Early localized Lyme disease (N= 60) | 27 | 6 | 33 | 0 | 29 | 29 | 62 |
| Early disseminated Lyme disease (N=30) | 0 | 0 | 0 | 0 | 0 | 0 | 0 |



Pillar 4 (Patient and Community Engagement, Training & Knowledge Translation)

(CO-LEADS: Cécile Aenishaenslin, Ryan Egan, Janet Parsons & Tamara Rader)

Pillar 4 has been able to continue its work, with some delays, despite the challenges presented by the pandemic and the secondment of researchers to COVID-19 related research. We have completed all interviews and analysis for the national healthcare practitioner study on the current diagnostic and treatment approaches to both acute and post treatment Lyme disease, and the resources they use to inform their approaches and decisions. There has been continued engagement with patient partners on all stages of the research study. At multiple meetings patient partners provided valuable feedback and recommendations on the design and implementation of interviews. Lyme disease patients contributed to the study by completing an anonymous survey indicating potential health practitioners to approach for recruitment into this study. As of August 31st, 2023, a draft of the manuscript has been completed and feedback will be obtained from patient partners and researchers engaged in this study.

The Knowledge Translation and Training (KTT) porthole will be shaped by future research directions of the network (i.e., expansion to include tick-borne diseases). For this reason, further development of the KTT porthole is on temporary hold until network and stakeholder discussions occur later in the fall 2023 and throughout 2024. The KTT porthole is envisioned as a national resource for consolidation and translation of primary (often controversial) Lyme disease research data. A proof of concept will eventually be developed for one (1) module, along with creating the platform infrastructure to allow for future modules to be added when additional funding is secured. Consultation with network scientists, and both internal and external patient and community stakeholders will occur. The results of the Pillar 4 focus group discussions, Brokered Dialogue project, grey literature review, and systematic review will help to shape the initial discussions. We will also solicit external feedback from Lyme advocacy groups and other external community stakeholders, including input from our Indigenous communities. The KTT porthole will also help to provide a platform for Lyme advocacy groups and Lyme disease patients/caregivers to connect and seek resources without necessarily becoming a member of CLyDRN or being a part of Patient and Community Advisory Committee (PCAC) or Community Engagement Committee (CEC). The platform can also be used for patients and caregivers to get together for peer support.



The Brokered Dialogue project focuses on patient and caregiver practices in managing Lyme disease (from diagnosis through treatment to ongoing management of chronic sequelae) and how these relate to the practices of those from other interested groups (e.g., clinicians, policymakers, researchers). The working group (which includes patient partners) has met during 2022-2023 and continues to contribute importantly to this study. Phase 1 data collection and analysis of individual interviews has continued this year, with 21 patient and caregiver participants recruited and recruitment of other groups currently underway. The rich data collected during Phase 1 are laying the foundation for Phase 2, which consists of filmed interactive interviews. We anticipate Phase 2 beginning in fall 2023. This study will employ the GRIPP2-SF checklist tool for reporting on patient and community engagement activities.

A doctoral student (Claire Hiscock), supervised by Pillar 4 scientists (Clara Juando-Prats and Janet Parsons) along with an Indigenous scholar (Professor Angela Mashford-Pringle) has been conducting a scoping review related to Indigenous people's experiences of Lyme disease, fibromyalgia and chronic fatigue syndrome. She has also been working on developing relationships with several Ontario First Nations community organizations with a view to eventually co-create a project that explores experiences and perspectives of First Nations people living in these communities regarding tick-borne illnesses. This relational work will be important to the future relevance of the network.

A qualitative research study was conducted to understand the drivers of healthy preventive behaviors against Lyme disease of the Canadian population. The study will investigate the impacts of tick bite exposure and the barriers/facilitators to the adoption of preventive behaviors amongst the general population. Interested Pillar 4 and PCAC members were invited to contribute to this project as co-researchers in winter 2020. The preliminary protocol was shared with Pillar 4 and PCAC members, and written feedback provided was incorporated into the final protocol. Twenty-two (22) focus group discussions were conducted with a total of 96 participants located in five regions with endemic Lyme disease in Canada: BC (n=5), MB (n=21), ON (n=22), QC (n=26), and NS (n=22). Interested PCAC members were also invited to participate in the interpretation and validation of results and in the writing of a co-authored publication (in preparation, expected to be completed in December 2023). The results from this study have been used to guide the development of a questionnaire for the pan-Canadian survey.

The pan-Canadian survey on exposure to ticks and knowledge, attitudes, and practices regarding Lyme Disease in the general population was conducted between January and



May 2023, and was stratified by province, gender, age, and education (n=3734). Participants answered questions related to ticks, tick-borne diseases (TBD), and tick bite preventive measures, and questions related to non-clinical impacts of ticks and TBD. Data analysis is ongoing, and a manuscript will be prepared based on this work (May 2024).

In addition to these two research projects, our team initiated a collaboration with eTick (Jade Savage) to develop a new knowledge translation webplatform dedicated to the prevention of tick-bites and TBD for the Canadian population (TickTOOL). This platform will include three main components: (1) a section with general information about tick-bites and TBD prevention, (2) an interactive quiz to evaluate users' knowledge on ticks and TBD, and (3) a risk self-assessment questionnaire that will allow users to receive personalized advice to improve their preventive behaviors and practices. The first component will be launched in fall 2023, and the two others are expected to be launched in spring 2024.

Pillar 4 Co-Lead Tamara Rader has been leading the implementation and evaluation of the GRIPP2-SF checklist tool (guideline to improve reporting of patient and public involvement in research) across the network along with PCAC member and CLyDRN Executive Committee member Nancy Garvey. We are amid a paradigm shift, actively involving patients, family caregivers, and community members in various research processes (citizen science). The patient and community perspectives are integrated into every step of the research process including developing research questions, defining research objectives, collecting data, and evaluating results, and we can work together through active collaboration and building consensus. The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results. Various projects within Pillars 1, 2, and 4 will employ the GRIPP2-SF checklist tool as part of the pilot roll-out throughout the network. The pilot projects completing the GRIPP2-SF checklist tool will be a good learning tool for other researchers in the network. PCAC members will facilitate and advise on the wording and format of the completed forms. This pilot initiative will provide an excellent opportunity for standardization of engagement efforts in reflective research practices across the network and can be used by all research teams when submitting papers for publication.

Pillar 4 next steps involve: (1) completion of the national healthcare practitioner manuscript prior to receiving feedback from patient partners and researchers, before submitting the manuscript for publications; (2) further discussions with the network and stakeholders for the future and development of the KTT porthole; (3) completion of the



Brokered Dialogue project; (4) designing and conducting the scoping review focused on Indigenous experiences and perspectives on Lyme disease; (5) completion of the qualitative healthy behaviours research manuscript, prior to receiving feedback from patient partners and researchers, before submitting the manuscript for publications; (6) data analysis and completion of the manuscript for the Pan-Canadian survey study; (7) rolling out and evaluating the GRIPP2-SF checklist tool in a number of pilot projects; (8) outreaching to Lyme disease advocacy and support groups; (9) onboarding new members (patient, family caregivers, and community partners) into PCAC and CAC; and (10) increasing participation of internal and external stakeholders at CLyDRN events.



Patient and Community Advisory Committee

(CO-LEADS: Clara Juando-Prats & Tamara Rader)

In line with the vision, mission, and goals of the Canadian Lyme Disease Research Network (CLyDRN), the Patient and Community Advisory Committee (PCAC) has focused its activities and efforts on developing and strengthening the patient engagement strategy designed and implemented in 2019. In addition to the ongoing activities started during the first two years after the network was funded, the PCAC members have been an important part in envisioning and leading the future of the CLyDRN to move forward in the development of a network that addresses the current reality and landscape of accessing diagnosis and care of not only Lyme disease but tick-borne diseases.

Members

Today, the PCAC has 50 active members engaged in different roles and capacities, 13 of them joined the network during the past year. The PCAC co-chairs and a member have regularly conducted orientation sessions with individuals interested in collaborating with the network. We continue working and putting our efforts on diversifying the composition of the PCAC in terms of geographical representation, gender, age, and cultural background and we are currently continuing to achieve this goal.

There are different roles in which the patient partners are collaborating with the network: 1) leadership within CLyDRN, 2) visioning and designing, 3) consulting, 4) research partners and collaborators, and 5) providing lived experience knowledge. The active members fulfill one or more of these roles based on their availability and skills.

Outcomes and Activities

During the past year, we hosted five PCAC meetings, allowing for a break in December and summer. The PCAC meetings focused on sharing network updates, presentations on preliminary results or research being conducted by network members, approving the research design of a co-created clinical study by Pillar 1, and two interactive brainstorming sessions to identify and match members priorities with current funding opportunities.

PCAC members continue to make pivotal contributions to the work of the network through the variety of roles. The PCAC patient partners are co-leading the development of the research conducted in Pillar 1 and in Pillar 3. With the Pillar 2 scientists, PCAC



patient partners are collaborating with the modelling and intervention working groups. Within Pillar 4, PCAC patient partners provide feedback, recommendations, and guidance on the Brokered Dialogue through the research working group. PCAC members co-designed the program and supported the organization of the Lyme Disease Awareness event in May 2023. The leadership of PCAC members was crucial in the planning and running of the CLyDRN Annual General Meeting in November 2022 as well as in the strategic and envisioning CLyDRN workshops that took place in the fall of 2022 and spring of 2023.

Special attention has been put in the planning of the implementation of the GRIPP2-SF reporting guideline across the network. These reporting guidelines will add consistency and rigour to the network's patient and community engagement practices. This initiative, led by two patient partners, is starting to be piloted in Pillar 1 and 4, and will be extended to the full network until the Spring of 2024. One graduate student from the Dalla Lana School of Public Health – University of Toronto – is being hired to support this work. In addition to this, the PCAC members have been working closely with the Community Engagement Committee in the mapping of strategic partners and in the design of the engagement and activities plan.

2023-2024 Plan

During the next reporting period the PCAC efforts will focus on ensuring that first, the needs and realities of patients and families are integrated in the future of the CLyDRN and across all levels -prevention, diagnosis, and treatment, second, new research funding applications are submitted in partnership with PCAC members and other community members and clinicians, and third, that the reporting research activities of the current network members are guided by the GRIPP2-SF checklist.



Community Engagement Committee

(LEAD: Lisa Dias)

In the Fall of 2022, the Community Engagement Committee (CEC) connected with a cottagers association, the Federation of Cottagers' of Ontario Associations (FOCA). FOCA leaders were interested in sharing information and asked that a CLyDRN present at the organization's annual general meeting (AGM). The CEC reached out to network researchers and Dr. Manisha Kulkarni expressed interest in this community engagement opportunity. On March 4, 2022, Dr. Kulkarni presented a talk at FOCA's AGM titled *"Tick Talk: Tracking the spread of ticks that carry Lyme disease in Ontario"*.

From January 2023 until the present, the CEC lead has largely focused on supporting community engagement work in the planning of the TickNet Canada Scientific Symposium 2023. Along with two CLyDRN patient partners, the CEC lead formed a community engagement subcommittee to support the planning and programming of the TickNet Canada Symposium. This sub-committee met at least once a month to organize an engagement-specific panel presentation and engagement activities for symposium attendees. With input from CLyDRN's PCAC, this subcommittee organized a Patient and Community Engagement Panel presentation titled *"Meaningful Patient & Community Engagement: How integrating multi-stakeholder perspectives adds value across the research continuum, from research questions to patient care"*. The panelists include two CLyDRN patient partners, a citizen engagement advocate, a knowledge translation and implementation science researcher, and a clinical researcher.



Trainee Advancement Committee

(CO-LEADS: *Natasha Bowser & Katie Clow*)

The Trainee Advancement Committee (TAC) has two Co-Chairs, one of which is a trainee (Natasha Bowser) and the other a scientist (Katie Clow).

In September 2022, a virtual "Kick-Off" event was hosted to welcome new trainees, provide an opportunity for networking, and gather input for the upcoming TAC programming for the academic year. An online survey was also distributed to gather information if trainees were unable to attend the event.

TAC subsequently hosted the following webinars:

- *"Lyme disease from the veterinary perspective"* with Dr. Katie Clow (October 2022).
- *"Laboratory diagnosis of Lyme disease and other tick-borne diseases"* with Dr. Mohammed Morshed (December 2022).
- Networking Event (February 2023).
- *"Host sampling methods"* with Dr. Ariane Dumas (March 2023).

TAC members also had an opportunity to attend the 2022 CLyDRN AGM and the programming during Lyme disease awareness month. Numerous trainees also presented at these events. All webinar presentations were recorded and uploaded to the CLyDRN members portal so those trainees who could not attend had access to the webinars.

The first annual TickNet Canada Symposium is scheduled for October 24-25, 2023 in Toronto, ON. We are hoping for a large trainee presence to share research, network, and plan the next events for TAC.



Project Grants Committee

(CO-LEADS: Rob Colautti, Clara Juando-Prats, Maarten Voordouw & Terrie Wainwright)

The Project Grants Committee (PGC) met with PCAC on Feb 8, 2023, and then held a joint virtual community consultation on Feb 15, 2023, to discuss research priorities with the broader patient/advocate community. The brainstorming session is summarized in a Google Jamboard file:

https://jamboard.google.com/d/1FKs7wkyjwSw3R5z-iBrtdqGRsJwtN0Xw_xPJPVi2Jwc/edit?usp=sharing

Each of the notes at the above link were posted by the patient/advocate community and covered a variety of topics and questions. A few themes that emerged were:

1. Questions about practitioner training and standards of practice for diagnosis and training.
2. Assessing and improving diagnostic tools.
3. Addressing tick-borne disease more generally (including Lyme, but not exclusively).

The PGC supported a New Frontiers Research Fund Exploration (NFRFE) grant led by Tim Salomons and Rylan Egan, based on priorities identified by PCAC members. This is a small exploratory grant from 2022 that was edited and re-submitted based on reviewer and patient/advocate feedback. Unfortunately, the grant was again not funded. The main concern of the reviewers was that the budget was not sufficient for human patient work. Based on this, Drs. Salomons and Egan are reluctant to apply again. Rob Colautti has reached out to Rylan Egan, Clara Juando-Prats, and Janet Parsons about applying to the upcoming competition, but there is not yet a clear plan for a proposal.

The PGC reached out to the leadership of CLyDRN to discuss the possibility of doing a NFRFE on whole-microbiome analysis of ticks, based on the recent paper in *mSystems* (<https://journals.asm.org/doi/full/10.1128/spectrum.01404-23>). We also posed the idea of a NFRF Transformation or NFRF International grant (<https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/index-eng.aspx>) to support new research and networking with CLyDRN/TickNet. However, there was not sufficient interest from the CLyDRN leadership to move forward.



In January 2022, the Committee supported a student-run case competition on the "*Emerging Disease Genetics and Ecology of Lyme Disease*", or "*EDGE of Lyme*". A follow-up event is currently planned for September 2023. This is an education/outreach event to promote awareness of tick-borne diseases and engage students from different disciplines to collaborate on a problem related to tick-borne diseases. The weeklong event begins with two days of lectures and workshops by scientists, patients, and advocates from CLyDRN and other organizations.

The PGC and Queen's University participated in *Science Rendezvous*: a virtual and in-person event for children and families held at various sites across Canada in May 2023. The Queen's research team shared information with the public on tick safety and raising awareness for Lyme disease through various activities.

The PGC has decided to suspend activities for the coming year, but individual members will continue to be involved in other CLyDRN activities.



CLyDRN Events

Annual General Meeting

(Planning Committee: Dr. Catherine Bouchard, Dr. Natasha Bowser, Dr. Rob Brison, Dr. Lisa Dias, Veronica Harris-McAllister, Dr. Clara Juando-Prats, Dr. Patrick Leighton, Dr. Janet Parsons, Pamela Scott-Crace & Terrie Wainwright)

The Annual General Meeting (AGM) was held virtually on November 2, 2022. Our plenary speaker was Dr. Lars Eisen who presented on "Prevention of tick bites and tick-borne infections". 13 students and trainees provided speed oral presentation at the AGM throughout the day. The panel discussion was on the topic "From research to better outcomes: mobilizing patient knowledge and experience". The panelists consisted of Pamela Scott-Crace (moderator) and Dr. Catherine Bouchard, Dr. Francois Milford, Sarah Merkley, Dr. Janet Parsons & Ariane Quintal (panelists). Pillar and committee updates were provided about the network's research projects, activities and initiatives carried out during the last fiscal year (2021-2022). The next AGM will be held in person in Toronto, ON (October 25, 2023) at the TickNet Canada Scientific Symposium.

Lyme Disease Awareness Event

(Planning Committee: Dr. Lisa Dias, Athina Hall, Veronica Harris-McAllister, Ruth Peters, Molly Praest & Terrie Wainwright)

The CLyDRN Lyme Disease Awareness Month is a great opportunity to help raise awareness for Lyme disease and to let Canadians know all about the amazing work that our network, external research groups, and Lyme advocacy groups have been doing to help raise awareness, demystify and "Take a bite out of Lyme". Throughout the month of May 2023, 21 speakers delivered 18 presentations on various Lyme disease and tick-borne disease topics:

- *How are Canadians adapting to the emergence of ticks and tick-borne diseases?* (Dr. Natasha Bowser-PhD Student)
- *Trends in tick surveillance and tick-borne diseases in BC* (Hannah Caird, Dr. Erin Fraser, Stefan Iwasawa & Quinn Stewart)
- *BC Veterinarian and Vet Tech Survey on Ticks, Tick-Borne Diseases & Passive Surveillance* (Steph Cooper-Master's Student)

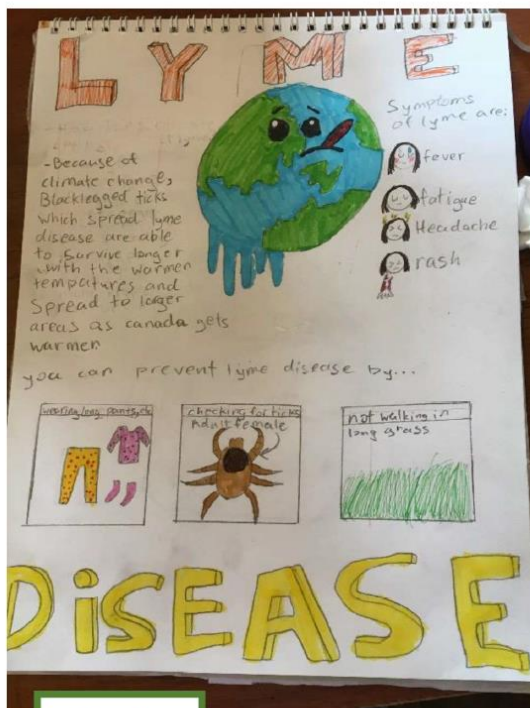


- *The ecology and epidemiology of Lyme disease in Western North America* (Dr. Susan Cork)
- *Why Lyme Patients use Naturopathic Medicine* (Dr. Carissa Doherty)
- *What's New in Tick-Borne Diseases in Nova Scotia* (Dr. Todd Hatchette)
- *Long term antibiotics for Lyme disease with persistent symptoms - a pilot project with 468 patients* (Dr. Amir Khadir)
- *Clinical Presentation and Outcomes of Children Treated for Lyme Arthritis: Experience from a Large Pediatric Cohort in Nova Scotia, Canada* (Jenna Nauss-Medical Student)
- *Lyme disease emergence with climate change – what will be the economic burden for Canada?* (presented by Dr. Nick Ogden on behalf of the research team (Ogden N.H., Dumas, A., Rafferty, E., Gachon, P.)
- *Neck Instability and Lyme disease: the potential connection* (Karen Orth)
- *Not TICKing the right boxes - My experience with Lyme and Co-Infections* (Dena Palamedes)
- *Hacking Lyme Disease: Action Steps for Recovery* (Dr. Marty Ross)
- *Potential Connection of Borrelia Infection and Breast Cancer* (Dr. Eva Sapi)
- *Five years of eTick data: highlights and outlook* (presented by Dr. Jade Savage on behalf of the research team (Jérémie Bouffard (Bishop's University), Dr. Étienne Clabaut (Université de Sherbrooke), and Dr. Jade Savage (Bishop's University))
- *A scoping review of modern Lyme Disease prediction methodologies* (Danny Szaroz-PhD Student)
- *Spirochete load in the host and tick is critical for transmission of Borrelia burgdorferi sensu lato* (Dr. Maarten Voordouw)
- *Lyme Carditis: 2023 Update on Clinical Management* (Dr. Rachel Wamboldt)
- *Detecting Lyme Disease Sooner: Using Proteomics to Identify Early Biomarkers* (Chang Xing Jian)

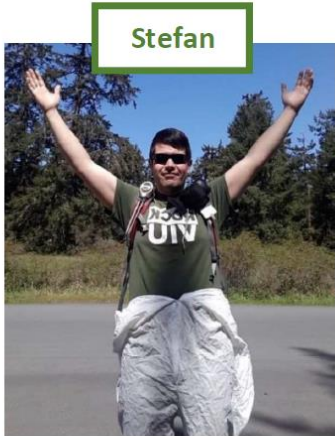


On average 30-35 participants (patients, family caregivers, Lyme advocates, community members, scientists, students, and trainees) tuned in each day to listen to the presentations. The presentations were recorded, and the videos were uploaded onto the members portal on the CLyDRN website to allow CLyDRN members an opportunity to watch any of the webinars missed. During the event we also held a photo challenge: wear green, take a photo, and share it with us to help spread awareness of Lyme disease. In total three (3) photo/drawing entries (see photo below) were received for the May event competition, and each entry received a \$25 Starbucks e-gift card (donated by the CLyDRN Network Management Office).

Draw Winners...



Sonja



Stefan



Jeff



Network Leads Workshops

(Planning Committee: Dr. Rob Brison, Dr. Lisa Dias, Veronica Harris-McAllister, Dr. Clara Juando-Prats, Dr. Patrick Leighton & Dr. Janet Parsons)

Network Leads workshops were planned throughout the year to allow the CLyDRN Executive Committee, Network Leads, and identified key internal/external stakeholders to start planning for future network activities, hold preliminary network visioning exercises, and start to search for funding opportunities to sustain and grow the network over the coming years and evolve into TickNet Canada. Workshops were held in person in Toronto Ontario on October 27, 2022 and in Ottawa, Ontario on April 20, 2023. A post symposium workshop has also been planned for October 26, 2023.

TickNet Canada Scientific Symposium

(Planning Committee: Dr. Adrian Baranchuk, Dr. Catherine Bouchard, Dr. Natasha Bowser, Dr. Heather Coatsworth, Dr. Susan Cork, Dr. Lisa Dias, Dr. Christopher Fernandez, Dr. Erin Fraser, Athina Hall, Veronica Harris-McAllister, Stefan Iwasawa, Dr. Emily Jenkins, Dr. Clara Juando-Prats, Dr. David Langlais, Dr. Patrick Leighton, Dr. Muhammad Morshed, Molly Praest, Pamela Scott-Crace, Audra Stitt, Dr. Maarten Voordouw & Terrie Wainwright)

The inaugural TickNet Canada Scientific Symposium will be held in person in Toronto, ON during October 24-25, 2023. It is estimated that ~110 people will attend the two-day event. A social (meet and greet) has been planned the evening before the event. Students and trainees have planned a networking event at a local establishment and the patient and community partners have also planned a small dinner together during the event. The plan is to rotate the location of the symposium each year from Central Canada (2023) to Western Canada (2024) to Eastern Canada (2025) and back to Central Canada (2026).

A broader planning committee consisting of 21 members was formed in January 2023 and meetings were held monthly. Sub-committees were formed to help roll out the checklist of activities over the last year: local organizing sub-committee, scientific program sub-committee, trainee engagement sub-committee, and community engagement sub-committee.

