CANADIAN LYME DISEASE
RESEARCH NETWORK

A YEAR IN REVIEW

292 Members

31 Patient Partners

45 Publications

3 Book Chapters

9 Reports

7 Guidelines

110 Presentations

38 Interviews

69 Students & Trainees

$1.4M New Funding

544 Stakeholders involved in various stages of Research Process

Featured in this Review:

- **Director's Message**
- **Pillar 1** *(Diagnostics)*
- **Pillar 2** *(Prevention & Risk Reduction)*
- **Pillar 3** *(Clinical Science & Health Service Research)*
- **Pilar 4** *(Patient and Community Engagement, Training & Knowledge Translation)*
- **Patient & Community Advisory Committee**
- **Training Advisory Committee**
- **Fundraising Committee**
- **Members Survey**
- **Lyme Disease Awareness Month**
- **Reflections from the Event Planning Committee**

Message from Director...

The past two years have challenged us in ways we could not imagine. It has made us adapt to new realities during a global pandemic, and it has inspired us to never give up during our journey to improve the prevention, diagnosis, and treatment of Lyme disease in Canada. But most importantly, it has made us proud of what the Canadian Lyme Disease Research Network (CLyDRN) has accomplished and can achieve together in a time of great crisis. We stand united as patients, family caregivers, scientists, community partners, and other stakeholders, and we are more committed than ever to our vision. This year has shown us that when we work together, we can overcome tremendous challenges and adapt quickly to support our commitment to excellence in research and education.

As we approach the mid-point of our Canadian Institutes of Health Research (CIHR) grant that has allowed us to establish the Network, we look forward to strategic planning and securing new funding opportunities that will sustain and grow the Network in the years to come. We are proud to be part of this Network, and we look forward to embarking on this journey together...we are all in this together.

Looking forward, we hope you join us for our virtual CLyDRN Members 2021 Annual General Meeting (AGM) that will be occurring on Wednesday, November 10, 2021 (1:00-4:00 PM EST) where our pillars and committees will provide an update on their activities over the past year. A year-in-review in the following pages provide a snapshot of CLyDRN's research and training activities over the past year that will be presented at our AGM. We just cannot say thank you enough for your tireless commitment and support to CLyDRN.

Kieran Michael Moore, MD, CCFP(EM), FCFP, FRCP(C)
Professor, Department of Emergency and Family Medicine, Queen's University
Principal Investigator and Director of the CIHR funded Canadian Lyme Disease Research Network

Pillar 1 (Diagnostics)
(CO-LEADS: Twylla Bird-Gayson & Tara Moriarty)

The 7-step priority setting process framework was developed in October 2019 by the patient partners and the scientists to identify and prioritize research gaps related to Lyme disease diagnosis. The final step was completed in January 2021 which included the selection of the final 3 top patient priorities as a result of a process based on current guidelines. The identified problems were: (1) Lyme disease testing is unreliable; (2) current testing modalities lack adequate sensitivity and specificity to accurately diagnosis Lyme disease; and (3) the two-tiered serological testing yields inconsistent results among patients that share similar tick exposure histories, clinical portraits (e.g., bloodwork not related to Lyme disease, symptoms, level of functioning), and who previously had erythema migrans rash.

A sub-working group of scientists met on two occasions to discuss the identified patient priority projects and to start to conceptualize a possible study design and project to discuss with the Pillar 1 patient partners and Patient & Community Advisory Committee (PCAC) for feedback before a protocol is developed.   To prevent any further delays in initiating the project, since the scientists are still inundated with COVID-19 clinical and research priorities, a consultant (a clinical epidemiologist with experience working with patient and family advisory groups) was hired in May 2021 to help develop the study design and methodology, budget, protocol, attendant documents, and complete the applications to submit to REBs to help roll out the project for Pillar 1 patient partners and scientists.

The consultant has been leading the discussions between the scientific leads and patient and family partners to identify and determine consensus on the ultimate research goal based on the priorities identified by the PCAC. Several meetings have occurred to date. The consultant, scientists, and Pillar 1 patient partners will be presenting their ideas to PCAC in the coming weeks and PCAC will be voting to reach a consensus to support one of the presented proposal options. Pillar 1 is aiming to develop and finalize their protocol and supporting documentation for submission to the REB by January 2022 with full study roll-out occurring by spring/summer 2022.

Pillar 2 (Prevention & Risk Reduction)
(CO-LEADS: Manisha Kulkarni, Patrick Leighton & 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: the Canadian Lyme Sentinel Network (CaLSeN), the Longitudinal Risk Study, and the Risk Reduction Innovation Program.

Pillar 2 published the 2019 results (active tick surveillance in 96 sites across 14 sentinel regions) from the CaLSeN in the October 2020 Canadian Communicable Disease Report (https://doi.org/10.14745/ccdr.v46i10a08). This paper documents our experience developing CaLSeN, the first coordinated national active surveillance initiative for tick-borne disease in Canada. Through multidisciplinary collaborations between experts in each province, the pilot year was successful in establishing a baseline for Lyme disease risk across the country, allowing future trends to be detected and studied. Active surveillance did not occur in spring/summer 2020 due to the pandemic as scientists and trainees were not allowed to carry out field work, nor enter federal and provincial parks, and/or cross provincial borders. Teams from the University of Montreal, University of Ottawa, University of Guelph, University of Manitoba, University of Saskatchewan, BC Centre for Disease Control, and University of New Brunswick, who participated in the 2019 field season, have participated in monthly meetings since January 2021 to finalize plans for the start of field activities in June 2021. New surveillance partnerships in 2021 included the Centre for Coastal Health (BC), University of Calgary (AB), and Acadia University (NS). Adapted field research protocols piloted for COVID-19 mitigation in 2020 will allow us to proceed with field work while respecting government and university health and safety protocols. We have also initiated processes to refine the multi-criteria decision analysis for selection of additional sentinel sites for expansion of CaLSeN in 2021, as well as the process for establishing data sharing agreements with external parties wishing to use CaLSeN data. We are currently in conversations with a partner to enhance the tick surveillance across Canada with the possibility of additional funding over 3-5 years which will allow the CaLSeN to further expand the number of sentinel sites currently under surveillance within the CaLSeN. Provincial and regional public health partners in all sentinel regions resumed surveillance activities in summer 2021 despite ongoing COVID-19 restrictions, carrying out 100 site visits across 14 sentinel regions.

The Longitudinal Risk Study consists of two activities: the retrospective case-control study and the prospective case-control study. The retrospective case-control study data analysis will commence in the summer 2021 and will be accessing the Public Health Ontario Laboratory's Lyme disease cohort dataset that has been linked to health administrative datasets held at ICES. Activities for the retrospective case-control study are proceeding now that the dataset has been created, and the PhD student at the University of Ottawa will start data analysis using a remote data link. We anticipate the completion of this study by December 2021.

The purpose of the prospective case-control study is to identify and estimate the significant determinants of Lyme disease risk and to assess differences in knowledge, attitudes, and practices (KAP) related to Lyme disease. We will also assess how Lyme disease risk, its determinants, and KAP change over time and space. The study protocol was finalized in the spring 2021 based on the revised Pillar 3 COHORT study design and has organized recruitment of matched controls to be managed by local research teams at the Kingston, ON and Lunenburg, NS recruitment sites under Pillar 3. Eligible cases and controls will be recruited from Emergency Departments/Urgent Care Centres at the Kingston Health Sciences Centre (ON) and Lunenburg Fishermen's Memorial Hospital (NS), beginning in the spring 2022 over a period of two years. The study will collect data from 90 cases of early localized Lyme disease and early disseminated Lyme disease participants enrolled between the two sites (n=60 and n=30, respectively). Data will be collected from Lyme disease cases at baseline, 12-months, and 24-months while healthy control participants will have information collected at baseline only. Discussion is ongoing regarding adding late-disseminated Lyme disease participants (data extracted from COHORT study under Pillar 3), adding follow-up visits for healthy controls at 12-months and 24-months, and increasing the number of healthy controls enrolled into the prospective case-control study. The current study protocol entails the collection of data from 90 Lyme disease cases and 180 matched healthy controls.

The Risk Reduction Innovation Program consists of two working groups: the Innovation/Intervention Working Group and the Modeling Working Group. The Innovation/Intervention Working Group formulated a work plan to utilize the seed funding for a project focusing on the cost-utility modeling and multi-criteria decision analysis for rodent-targeted interventions. Project activities are planned to start in fall 2021. The Innovation/Intervention Working Group will also add collaborators from municipalities, pest management industry, US agencies, members of the public, Patient & Community Advisory Committee, and other community stakeholders, including Indigenous communities to the working group.

The Modelling Working Group formed its core membership consisting of 9 Canadian CLyDRN members. Additional preferred members were identified (1 US-based CLyDRN member, 3 Canadian non-members, and 4 international non-members). In addition, the first teleconference was completed, and a broad summary of tasks and objectives were identified including initial discussions on the development of seed funded projects for the development of pan-Canadian models of Lyme disease risk which will be submitted to the CLyDRN Executive Committee for review in the Winter 2022 to utilize the seed funding. A second teleconference will be scheduled in the summer/fall 2021 once capacity opens in the scientists' schedules. All modeling/mapping scientists are still inundated with COVID-19 priorities.

Pillar 3 (Clinical Science & Health Service Research)
(CO-LEADS: Rob Brison, Derek Leslie, Mark Loeb, Samir Patel, Elizabeth Stringer & Beate Sander)

Pillar 3 has made important progress on the CLYME (Biobank) and COHORT studies. We finalized study documents for the CLYME (Biobank) and COHORT studies in the spring 2021. Ethical and institutional clearances and special exemptions needed during COVID-19 were obtained to commence the projects at the Kingston, ON recruitment site. The Lunenburg, NS recruitment site has submitted their applications to the local REB (research ethics board) for both studies; final ethical clearances are still pending.

OSCAR (electronic data capture for the CLYME (Biobank), COHORT, and Pillar 2's prospective case-control studies) was completed along with setting up linkage to McMaster's RedCap database for transferring data directly to McMaster for the COHORT study. The sample inventory management system (ELAB journal) was set up for the specimen biobank and the lab manual was finalized for standard operating procedures (SOPs) for sample collection, sample processing, and sample storage related to culturing borrelia growth, PCR (polymerase chain reaction), PBMCs (peripheral blood mononuclear cells), PAXgene, plasma, serum, and urine, cerebrospinal fluid & aspirates collection from samples collected and processed the same day and samples collected and held overnight before processing the following day needed for the CLYME (Biobank) and COHORT studies. In addition, McMaster University has established the staining panels that will be used for measuring immune populations in PBMCs and assessing their activation state. Working with the central group at Queen's University, McMaster University has confirmed that stains on materials cryopreserved at Queen's University can be shipped successfully to McMaster University without damage to the blood cells.

Changes in site principal investigators (PI) was initiated at the Kingston, ON and Lunenburg, NS recruitment sites. Dr. Rob Brison assumed the PI role from Dr. Michael McDonnell for the Kingston, ON recruitment site and Dr. Elizabeth Stringer assumed the PI role from Dr. Todd Hatchette for the Lunenburg, NS recruitment site.

The CLYME (Biobank) study aims at creating a national multicentre biobank to facilitate future research activities. There will be 200 Lyme disease patients and 200 healthy controls recruited for the initial biobank repository. Data will be collected at baseline and 1-month. The COHORT study aims at describing the physical and mental health outcomes of Lyme disease, and to assess predictors of long-term outcomes and factors associated with delayed recovery. Patient-relevant outcomes include physical and mental functioning, fatigue, depression, and neurocognition. There will be a full range of Lyme disease cohorts: Group A (confirmed Lyme disease (early localized (N=60), early disseminated (N=30), late disseminated (N=30))), Group B (hypothesis generating-comparison group (flu-like illness but without Lyme disease rash and Lyme disease test positive (N=30)), Group C (secondary cohort-comparison group (symptoms of Lyme disease and Lyme disease test negative (N=60))), and Group D (healthy controls (N=30)). Data will be collected at baseline, 1-month, 3-months, 6-months, 9-months, 12-months, and 24-months.

Research teams have been trained on all aspects of the study, including the neurocognitive tests, ELAB and OSCAR, and mock dry runs have occurred. On May 31, 2021 participant recruitment for the CLYME (Biobank) and COHORT studies commenced at the Kingston, ON recruitment site as part of a pilot program. The study teams agreed to pilot both studies over the spring/summer 2021 and review lessons learned in the fall 2021. To date 14 participants have been screened and 8 participants have been enrolled into the COHORT study, while 14 participants have been screened and 14 participants have been enrolled into CLYME (Biobank) study.

The COHORT study is currently on hold for additional participant recruitment (only participants enrolled to date will be followed); only the CLYME (Biobank) study continues to recruit participants as there are only 2 visits (Baseline & 1-month). Over the fall/winter the COHORT study protocol will be reviewed to determine if the length of the study visits can be significantly reduced by decreasing the number of neurocognitive tests, decreasing the number of questionnaires administered, removing other study procedures, and/or finding efficiencies in the process. The COHORT study is very time-consuming (~4 to 4 ½ hours per visit for each participant) and all data collection occurs in-person for clinical assessments, questionnaires, and neurocognitive testing. The goal is to get the

study visit length to under 2 hours to be able to double the number of participants recruited and followed daily. The COHORT study will re-launch at the Kingston, ON recruitment site in the spring 2022. The Lunenburg, NS site has initiated contact with the multiple stakeholders involved in the study including importantly the respective labs for sample processing in Lunenburg, Bridgewater, and Halifax. Participant recruitment for the CLYME (Biobank) and COHORT studies at the Lunenburg, NS recruitment site is expected to launch in the spring 2022.

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 and published a systematic review of research into the effectiveness of Lyme disease knowledge translation and training of the general population and health care practitioners (https://doi.org/10.1080/14635240.2021.1920045). We have completed a grey literature review of global information, training resources, and courses available to healthcare practitioners in Canada. The review has been completed and the manuscript was recently approved for publication.

Sixteen (16) virtual interviews with national healthcare practitioners 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, were completed. These interviews and health practitioner recruitment is ongoing, and slightly delayed due to COVID-19 and the unavailability of health practitioners. We will continue to use our networks and snowball sampling to recruit. Continued engagement continues with patient partners on all stages of this 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.

Development of the Knowledge Translation and Training (KTT) porthole has been delayed due to the stated purpose of translating CLyDRN research (which has been delayed). The project will continue in earnest through a full process of consultation with Network scientists, and both internal (Patient and Community Advisory Committee (PCAC) and

Community Engagement Committee (CEC)) and external patient and community stakeholders. 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 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. This task will take 12-18 months to complete. Starting in the fall 2021 an internal working group that will include patient partners will start mapping the approach and design of the KTT porthole. Input from CLyDRN Executive Committee, Pillars/Committees Network Leads, PCAC, and our new CEC will be collected on the top topics to cover. In addition, 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 Brokered Dialogue project has been paused/delayed by COVID-19 because of our inability to conduct the in-person filmed interviews central to this project and the REB (research ethics board) was not accepting new non-COVID projects. Our working group (which includes patient partners) met during 2020-2021 and in consultation with them and the PCAC, we have refined the focus for this work 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 other stakeholders (i.e., clinicians, policymakers, others). The project is now ramping back up and preparing for REB submission and will seek further input from our working group. To move this project forward, we are planning a first phase of in-depth audio recorded interviews, which can be collected remotely (by phone or ZOOM) with patients, caregivers, and other stakeholders. The data collected will serve as a foundation for the filmed brokered dialogue proper (Phase 2). Phase 1 can be completed in the fall/winter of 2021/2022, with Phase 2 beginning in the spring of 2022. Our filmmaker has recently developed a method for remote filming, and we will work with them to see if this might be a viable alternative to in-person work. It is possible that restrictions to in-person data collection may persist and this remote option will help us mitigate potential impact.

We have completed community stakeholder mapping exercises with PCAC and scientific leads to help inform the development of the CEC. During the next year, we will focus on contacting potential community partners to develop the new Committee, including establishing and developing relationships with Indigenous communities. Active recruitment for the CEC will begin in the fall 2021 and continue thereafter.

Twenty focus group discussions will be held in four locations (BC, ON, QC and NS) with endemic Lyme disease in Canada as part of the qualitative research on healthy preventive behaviours study. The focus discussions were delayed due to travel and research restrictions. They are now scheduled to occur in the fall 2021. The study will investigate the impacts of tick bite exposure and the barriers/facilitators to the adoption of preventive behaviors amongst the general population. If travel and/or research restrictions are maintained during this period, the focus discussions will be conducted online. Hence, we do not anticipate more delays in the completion of this deliverable. Interested Pillar 4 and PCAC members were invited to contribute to this project as co-researchers in winter 2020 (before COVID-19 impacts). The preliminary protocol was shared with Pillar 4, and written feedback provided. The final research protocol will be shared and discussed with Pillar 4 members and final amendments will be made before data collection. Interested PCAC members will be invited to participate in the interpretation and validation of results from this qualitative research in January 2022 and will be invited to participate in the writing of a co-authored publication. These results will be used to guide the development of a questionnaire that will be applied 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 has been delayed given that qualitative results from the focus group discussions are needed to consolidate the questionnaire. Data collection is now scheduled for summer 2022. This survey study will investigate the adaptation of the Canadian population to ticks and Lyme disease. This study will also allow to quantify tick exposure across Canada, and to test this indicator as an indicator of risk for Lyme disease. We do not anticipate other delays or risk related to this deliverable, given that the survey will be conducted online (web-based panel) and is not subject to restrictions of cancellation due to the pandemic. Interested Pillar 4 and PCAC members will be invited to contribute to this project as co-researchers. Data analysis will be conducted in fall 2022. The research protocol will also be shared with PCAC members for comments and discussion.

Next steps involve outreach to Lyme disease advocacy groups; continued recruitment of healthcare practitioners for qualitative research study; onboarding new members (patient partners) and increase participation of internal and external stakeholders at the fall 2021 CLyDRN Members annual general meeting; initiating the Brokered Dialogue project in the fall 2021; initiating the focus group discussions in four Canadian provinces in fall 2021; initiating the Pan-Canadian survey in summer 2022; establishing the CEC; and designing and conducting scoping review focused on Indigenous experiences/perspectives on Lyme disease.

Patient and Community Advisory Committee
(CO-LEADS: Clara Juando-Prats & Tamara Rader)

The Patient and Community Advisory Committee (PCAC) has been working since the beginning of the Network on engaging patients, caregivers, and members of the community in all aspects of the Network based on CIHR's Strategy for Patient Oriented Research (SPOR) Framework . PCAC's activities have focused on connecting with patients and caregivers across Canada and creating a community of patient partners. 2020 saw some changeover of patient partners, as some stepped back from intensive duties, because of other commitments or for personal reasons, and new patients joined the Network. During the past year, 88 people have contacted the PCAC through the open survey available through the CLyDRN website. 56 out of the 88 individuals indicated they are individuals living with Lyme disease and 13 of them indicated they were a friend or family member. Additionally, one referral was made through a Network member and a total of 59 people were invited to join the PCAC. Of the 59 people invited, only 7 individuals joined the PCAC and participated in one of the three orientation sessions conducted for new members, by the PCAC co-chairs and with the support of a PhD student in the Network. Today, the PCAC has 31 members which has resulted in an enriched and diverse range of perspectives, skills, and experiences advising and working with the rest of the CLyDRN members. Although only 31 patient partners sit on PCAC there are 2-3 times as many patient partners who belong to the Network in a passive role and attend Network events. PCAC was also involved with helping to identify relevant community stakeholders to join the new Community Engagement Committee. We are continuing to recruit new patient and caregiver members to the Network.

Since September 2020, several patient partners have taken on leadership roles in pillars and committees and/or now sit on the CLyDRN Executive Committee. We now have patient partners acting in Co-Chair/Co-Lead roles for Pillars 1-4 and PCAC. We aim to find additional patient partners to become Co-Chair/Co-Lead for the Fundraising Committee and Communications Committee by the end of 2021. We now have 3 patient partners sitting on the CLyDRN Executive Committee. We aim to add 3 additional patient partners by the fall 2021. Except for the Training Advisory Committee, Fundraising Committee, and Communications Committee, we have several patient partners involved in the four pillars and PCAC activities and participating in various sub-working groups. We aim for a minimum of 2 patient partners on every pillar, committee, working group, and special initiative projects.

The patient compensation guidelines were finalized in August 2020 for providing much-needed suggested compensation for different roles and levels of engagement by patient partners within the Network. The guidelines will also be used when team members are applying for new funding opportunities and creating budgets. The CLyDRN budget was revised in September 2020 to allocate some funding towards patient partners involved throughout the Network in leadership roles and participating in sub-working groups and special initiative projects. Funding was allocated for past roles in F2020 and F2021 and future roles in F2022 and F2023.

There is evidence that there continues to be active interest among patients in contributing their expertise to our Network. PCAC has been actively offering support and encouragement to members to collaborate across pillars, committees, and other sub-working groups and special initiatives. Patient partners continue to make pivotal contributions to the work of the Network through various advisory, collaborative, and/or decision-making role depending on their availability. For example, the PCAC has been able to complete a priority setting process over the last 16 months related to Pillar 1 research and is actively shaping the work of Pillar 4 on multiple projects. Of recent note is the leadership of PCAC members in planning and running last year's virtual AGM (November 2020), and the inclusion of patient partners in many presentation panels throughout the day. PCAC members also co-designed the 2021 Lyme Disease Awareness Month (May 2021) to increase the profile of the Network in the Lyme community.

We hosted 5 PCAC meetings, allowing for a break in December 2020 around the holidays, a break for members to prepare for the AGM in the fall of 2020, and a break in May 2021 so members could join the Lyme Disease Awareness Event month activities. These changes to the regular schedules were based on PCAC members' feedback. The PCAC has organized smaller working groups to work closely on the different projects mentioned above. As part of the engagement strategy to develop and strengthen communication between CLyDRN scientists and PCAC members, we have invited on a regular basis scientists and students from the Pillars to present and discuss their work; this has proved extremely beneficial and engagement for both groups and we will continue with this approach in the upcoming year.

One of the challenges faced by the PCAC is the difficulty to get representation from all provinces (e.g., Nunavut, Yukon, Northwest Territories, Newfoundland & Labrador), to engage with Indigenous communities, and to have gender and race diversity. A related challenge is the difficulty to partner with Canadian Lyme disease advocacy groups. In terms of engagement with Indigenous communities, our PhD student will make this a

focus of their doctoral research, possessing expertise in Indigenous public health. During the Lyme Disease Awareness Month, members of different advocacy groups attended the CLyDRN webinars and engaged in a discussion with attendants and presenters. During the next year the PCAC has the goal of initiating conversations with the advocacy groups and invite them to a PCAC meeting to create a space for learning, creating, and discussing.

We will also continue to look for relevant funding opportunities and will submit another grant application within the next 12 months, and we will begin writing and disseminating of the process and activities and lessons learned by the PCAC through the work done for and with the CLyDRN.

Training Advisory Committee
(LEAD: Katie Clow)

The Training and Advisory Committee (TAC) met in September 2021 to discuss the needs for the upcoming year. This was a highly beneficial meeting and helped determine the direction for the upcoming year. TAC offered four webinars over the academic year on a diversity of relevant topics:

- "*Tools for bioinformatics*" with Dr. Amber Rose Paulson on November 19, 2020;
- "*Accessing public health data*" with Dr. Marion Ripoche and Dr. Curtis Russell on December 10, 2020;
- "*Modelling the spread of ticks and tick-borne pathogens*" with Dr. Olivia Tardy and Dr. Isabelle Couloigner on March 25, 2021; and
- "*Health care practitioner perspectives on diagnosis and treatment*" with Dr. Rylan Egan, Ms. Emilie Norris-Roozmon, Ms. Madison Robertson, and Dr. Angela Coderre-Ball on April 29, 2021

We experienced several challenges this year. For some webinars, attendance was low (between 5-20 people). This has been a shared experience for many webinars as individuals are developing "Zoom Fatigue". Additionally, we struggled to secure presenters due to the ongoing demands of the pandemic on experts in the Network.

We have two co-chairs of this Committee, one of which is a trainee. The trainee co-chair (Benoit Talbot) stepped down in the spring of 2021 from their position and we will need to recruit a new co-chair. This may be a challenge, depending on interest in the Network.

Fortunately, we had a consistent following of students and trainees and thus a good pool of potential co-chairs to select from when we meet again in September 2021.

Additionally, we collaborated with CLyDRN's leadership and administration to facilitate student and trainee presentations to share updates and progress of their research projects at both the CLyDRN Members annual general meeting (November 4, 2020) and during the Lyme Disease Awareness Event Month (May 2021). Students and trainees had the opportunity to present at both events. Next year, we aim to continue with our webinar series and provide opportunities for new student and trainee engagement (virtual and in person) as they become available. All webinars and student/trainee presentations were recorded and uploaded to the CLyDRN members portal so those who could not attend have access.

Fundraising Committee
(LEAD: Rob Colautti)

This fiscal year the Fundraising Committee supported 3 grant applications (2 successfully funded) and discussed future funding opportunities to continue research started by the Network. We successfully secured new funding ($100,000) from the Ontario Early Researcher Award program to support a new project: genetics of range expansion in ticks and tick-borne pathogens. We also successfully secured new funding ($75,000) from the Queen's University Wicked Ideas grant program to support a new project. The long-term goal of this project is to improve the quality of life for people affected by tick-borne diseases. This will be done by identifying new therapeutic targets and eliminating misdiagnosis. The New Frontiers in Research Fund Letter of Intent that was submitted was not selected to move forward to a full application. Will re-apply in future competitions.

Our support of the myLyme.ca project brings to Lyme disease research in Canada new outside expertise in ecology, genomics, bioinformatics, cognition, and pain research. Support from CLyDRN enabled the core team of seven junior faculty (3x pre-tenure, 4x recently tenured) and to establishing a collaborative convergence research program in tick-borne diseases. None are established Lyme disease researchers, representing an important contribution of CLyDRN to highly qualified personnel development in tick-borne disease research in Canada.

Our focus for the next fiscal year will continue to be to identify funding opportunities and supporting collaborative grants involving Network members. An ongoing challenge has

been to inspire involvement from stakeholders to sit as members of the fundraising committee. This is particularly difficult in context of COVID-19, which limited opportunities for personal interactions and face-to-face discussions to build trust with stakeholders (e.g., at our annual general meeting). Currently we do not have any patient partners on this committee nor a patient co-chair/co-lead as there is no interest. We are working with PCAC to identify patient partners to join the committee over the next fiscal year. We are also looking to add stakeholders with expertise in fundraising to the committee and gain support from institutional advancement offices at the partner institutions as current chair does not have the resources or proper skillset to facilitate soliciting private and public donations to support the sustainability of CLyDRN. On the bright side, the necessary move to online meetings has normalized the use of Zoom and other communication technologies that will enable more frequent meetings with a smaller carbon footprint.

CLyDRN MEMBERS SURVEY

We need your input: *https://www.surveymonkey.com/r/YMP5VCM*
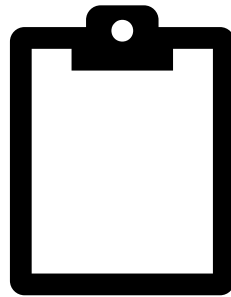
LYME DISEASE AWARENESS MONTH

Throughout the month of May 2021, 18 presentation sessions (12 pre-recorded videos from the November 2020 AGM and past trainee webinars and 6 live presentations) occurred on various Lyme disease topics. On average 5-30 participants tuned in each day to listen to the presentations. The new presentations were recorded, and the videos and slide decks were uploaded onto the members portal on the CLyDRN website; AGM video and the trainee webinar videos are already posted. An open forum was also held following the CLyDRN presentation but due to lack of participation from participants, an anonymous survey was circulated to all CLyDRN members and participants who attended the event (individuals who are not part of CLyDRN) to obtain feedback. Additional questions were added to help identify barriers to involvement with CLyDRN. The survey questions were vetted through the Patient & Community Advisory Committee for input. During the event we held a photo challenge: wear green or wear a green face mask, take a photo, and share it with us to help spread awareness of Lyme disease. In total five (5) photo/drawing entries were received for the May event competition, and each entry received a $20 Starbucks e-gift card (donated by the CLyDRN Network Management Office).

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 has been doing to help raise awareness, demystify and "*Take a bite out of Lyme*". We are still in the planning stages for our next event but wanted to reach out and see if any CLyDRN Members were interested in partnering in this virtual month of events that is slated to occur throughout May 2022. Exact dates/times are still to be determined for the various activities. We can work around CLyDRN Members schedules and availability.

The CLyDRN Event Planning Committee welcomes suggestions (topics, speakers, activities) for the event. Your participation can be to chat about your organization and the support and resources you provide to Lyme disease patients and their families, you can present on your research findings or be a part of panel discussion on an interesting topic, you can educate on Lyme disease diagnosis, testing, treatments, and prevention or any other platform/forum is welcome. If you know of any other groups or individuals we should reach out to include to make the event a success, please let us know. Our hope is this becomes an annual event, bringing our alliances together each May for a common cause. Please reach out to the CLyDRN Network Management Office (**clydrn@gmail.com**) with your ideas and/or if you are interested in participating in the event.

Reflections from the Event Planning Committee...

2020-2021 has been quite a year for many Canadians as we emerge from the pandemic and look forward getting our Network back on track. The pandemic caused significant disruption for research and innovation as scientists focused on COVID-19. But with every challenge come opportunities.   The Network created mitigation strategies and re-designed and modified projects which have allowed research activities previously side railed to reinitiate and rejuvenate progress and momentum on several key deliverables and milestones to get us back on track. We still have a long way to go but we have made many small steps forward. We are proud of our accomplishments to date. We have highlighted some of our achievements below:

1. The ability to host presentations virtually from various stakeholders was incredible. Researchers, students, trainees, patients, and family caregivers who volunteered time to participate, inspired many at the Lyme Disease Awareness events held in May 2021 and at the AGM held in November 2020.

2. The adaptability of the Network to work collaboratively, as various challenges emerged was fantastic to see and experience.

3. The development of various brainstorming and problem-solving platforms did promote meaningful and positive conversations.

4. Funding shortfalls have not prevented incredible research from being accomplished this year.

5. Strengthening of Pillar and Committee relationships, sharing knowledge to advance the science of not only Lyme disease but tick-borne disease as well.

Thank you for your continual support of our Network and of Lyme disease and tick-borne disease research. We hope you continue to participate in our future virtual and in-person events.

Nancy Garvey, Tamara Rader,
Terrie Wainwright & Veronica Harris-McAllister