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MEMBERS NEWSLETTER

DECEMBER 2021

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

CLyDRN Director Update...



Dr. Kieran Moore

Dr. Patrick Leighton

Dr. Rob Brison

Dr. Kieran Moore is leaving the Canadian Lyme Disease Research Network as he focuses on his new role as Ontario's Chief Medical Officer of Health. We are deeply grateful to have had Dr. Moore's guidance, tireless service, and unwavering leadership that has benefited the Network tremendously over the past 4 years. Dr. Moore played a major contribution in helping to form the Network and has served as the Network's inaugural Director until recently when he stepped down from the role.

As part of the transition plan that was recently endorsed by the Network's Executive Committee and Network Pillar and Committee Leads, Dr. Patrick Leighton (Université de Montréal) and Dr. Rob Brison (Queen's University) will become the next Co-Principal Investigators for the CIHR grant awarded back in 2018 and will jointly share leadership responsibilities. Many of you are familiar with Dr. Leighton who co-leads Pillar 2 (Prevention & Risk Reduction), which includes the Canadian Lyme Sentinel Network, and Dr. Brison who is the site investigator for the Pillar 2/3 COHORT, CLYME (Biobank), and PROSPECTIVE CASE-CONTROL studies occurring at the Kingston (ON) recruitment site. Dr. Leighton will become the next Network Director, effective immediately, and will be responsible for future planning for the Network (i.e., governance, strategic planning, sustainability, new research funding opportunities). Dr. Brison will focus on ensuring that the existing pillar/committee grant deliverables are met through Queen's University's obligations to our funding agency, CIHR, for our original \$4M grant.

Please help us congratulate Dr. Moore on his new role and thank him for all his contributions by signing the digital card: <u>https://www.groupgreeting.com/sign/73263e95b273e4f</u>. Please also help us welcome Dr. Leighton and Dr. Brison to their new leadership roles.



PILLAR UPDATES

Pillar 1

DIAGNOSTICS

The consultant continues leading the discussion between the scientific leads and patient and family partners to identify and determine consensus on the ultimate research goal for the patient-priority project. A presentation to the Patient & Community Advisory Committee for endorsement will be occurring in January 2022.

Pillar 2

PREVENTION AND RISK REDUCTION

The Canadian Lyme Sentinel Network resumed surveillance activities in summer 2021 despite ongoing COVID-19 restrictions, carrying out 115 site visits across 17 sentinel regions. Data analysis commenced for the retrospective casecontrol study in summer 2021 with anticipated completion of the study by December 2021. The prospective case-control study is on hold until spring 2022. The Innovation/Intervention Working Group finalized their project: cost-utility modeling and multi-criteria decision analysis for rodent-targeted interventions. The Modelling working group is still on hold.

Improve prevention, diagnosis, and treatment of LD in Canada

Pillar 4

PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

Systematic review and gray literature review published. Conducted 29 virtual interviews with national healthcare practitioners. Knowledge Translation Porthole Committee is currently being established. The online focus group discussions with members of the general public (high risk groups) in four Canadian provinces (BC, ON, QC, NS) have commenced. A total of 17 focus groups will be completed in October/November 2021. The Pan-Canadian survey will be initiated in the summer 2022. Preparing the REB submission for brokered dialogue project and commencing the foundational audio recorded interviews (Phase 1) in the coming months. The filmed interactive interviews (Phase 2) will commence later in 2022. The doctoral project commenced with a literature review on Indigenous experiences and perspectives on Lyme disease. Stakeholder mapping and outreach for the Community Engagement Committee has commenced. Next steps involve outreach to Lyme disease advocacy groups; onboarding new members (patient partners) and increase participation of internal and external stakeholders at CLyDRN events.

Pillar 3

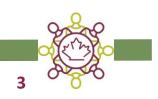
CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

COHORT Study:

9 participants completed their Baseline visit; 8 participants completed 1-month follow-up visit; 7 participants completed 3-month follow-up visit; 1 participant dropped out.

CLYME (Biobank) Study:

20 participants completed Baseline visit; 15 participants completed 1-month follow-up visit; 4 participants dropped out.



COMMITTEE UPDATES

CC

COMMUNICATIONS COMMITTEE

Activities currently on hold. Looking for new members to join this committee to help roll out activities. If interested in joining this committee, please reach out to the CLyDRN Network Management Office at <u>clydrn@kflaph.ca</u>.

PCAC

PATIENT AND COMMUNITY ADVISORY COMMITTEE

There are 32 active members. PCAC held advisory roles by providing feedback and input through surveys and discussions with Pillar 1-4 and the Fundraising Committee with different levels of engagement (co-design and collaboration). Various PCAC members hold leadership roles on the Executive Committee, Pillar Leads Committee, and Event Planning Committee (AGM and Lyme disease awareness events). PCAC is leading the implementation of the GRIPP2 tool for capturing patient engagement in research projects.

Improve prevention, diagnosis, and treatment of LD in Canada

FC

FUNDRAISING COMMITTEE

Supporting another application to the New Frontiers Research Fund (Exploration Grant) program. Organizing a Lyme "Hack-a-thon" for students. Edge of Lyme is a hack-a-thon style competition in which students from all disciplines form teams and collaborate to solve various problems in the world of Lyme disease. This event is set to take place January 22-29, 2022. FC continues to look for patient partners to join an advisory panel that will feed into various projects recently awarded funding through FC. FC also looking for new members to join and help roll out fundraising activities. If interested in either opportunity, please reach out to **Dr. Rob Colautti** (<u>robert.colautti@queensu.ca</u>).

TAC

TRAINING ADVISORY COMMITTEE

Natasha (Nofal) Bowser is the new trainee Co-Chair. Webinar planning for the academic year is still ongoing. If anyone is interested in presenting to TAC, please reach out to **Dr. Katie Clow** (kclow@uoguelph.ca). If you are an interested trainee (e.g., graduate student, postdoctoral student, resident) OR a supervisor with trainees that would like to access to TAC events, please send your name(s) and email address(es) to **Dr. Katie Clow** (kclow@uoguelph.ca).



RES<mark>EARCH A</mark>RTICLES, BOOKS & INTERVIEWS....

SYSTEMATIC REVIEW of LYME DISEASE

Article: Coderre-Ball, A. M., Robertson, M. A., Matzinger, E., & Egan, R. (2021). Training initiatives that enhance knowledge, attitudes, and practices regarding the prevention, diagnosis and treatment of Lyme disease: A systematic review. International Journal of Health Promotion and Education; 1-24. https://doi.org/10.1080/14635240.2021.1920045

GRAY LITERATURE REVIEW of LYME DISEASE

Article: Coderre-Ball, A. M., Sahi, S., Anthonio, V., Robertson, M., & Egan, R. (2021). Lyme Disease Training and Knowledge Translation Resources Available to Canadian Healthcare Professionals: A Gray Literature Review. Journal of Primary Care & Community Health; 12. https://doi.org/10.1177/21501327211050744

LYME CARDITIS

Article: Wang, C., Yeung, C., Enriquez, A., Chacko, S., Hanson, S., Redfearn, D., Simpson, C., Abdollah, H. & Baranchuk, A. Long-term outcomes in treated Lyme carditis. Current Problems in Cardiology. 2021 Jul 24. https://doi.org/10.1016/j.cpcardiol.2021.100939

Article: Baranchuk, A. Lyme carditis: things can get complicated when Lyme disease affects heart function. The Conversation. 2021 Oct 13. https://theconversation.com/lyme-carditis-thingscan-get-complicated-when-lyme-disease-affectsheart-function-167045

EMERGING ZOONOSES

Article: Talbot, B., Kulkarni, M.A. & Colautti, R.I. Convergence Research for Emerging Zoonoses*. Trends Parasitol. 2021 Jun; 37(6): 465-467. https://doi.org/10.1016/j.pt.2021.03.008

* Please reach out to the CLyDRN Network Management Office for a copy of the full article. Permission granted from authors. <u>Disclaimer</u>: this article can be shared with CLyDRN members only but cannot be posted publicly until summer 2022 due to embargo policies.

GUIDANCE FOR REPORTING INVOLVEMENT OF PATIENTS AND THE PUBLIC (GRIPP2)

Article: Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research BMJ 2017; 358: j3453. <u>https://doi.org/10.1136/bmj.j3453</u>

Publications

Have you recently published (journal article, book chapter, lead author/editor of a book, technical reports, policy briefs or policy guidelines)? Have you recently had one of your presentations or interviews with a journalist video-recorded? Please share your news and links with the CLyDRN Network Management Office so we can share with our members in future newsletters to help raise awareness and celebrate the impact of our members' work.



RESEARCH FUNDING OPPORTUNITIES (Lyme Treatment Foundation)

The Lyme Treatment Foundation

(https://lymetreatmentfoundation.org/) has officially funded its first research project with the University of Oxford. The title of the research project is *New pharmacological agents to treat persistent infections*. Check out this link for more details about the project: https://lymetreatmentfoundation.org/funded-research.

The Lyme Treatment Foundation is dedicated to funding research that will directly impact those suffering from Lyme disease and other tick-borne illnesses. Grant applications are accepted on a rolling basis: <u>https://lymetreatmentfoundation.org/research-grants</u>.

> For additional information, please email: <u>info@lymetreatmentfoundation.org</u>.

LYME DISEASE AWARENESS EVENT (May 2022)

The CLyDRN Event Planning Committee welcomes suggestions (topics, speakers, activities) for our next Lyme Disease Awareness Event that will be held throughout May 2022. The event 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". 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 with your ideas and/or if you are interested in participating in the event.

Miss out on the AGM...

To access the 2021 AGM video, please go to <u>www.clydrn.ca</u> and click "Login" at the top. Enter your email (username) and password and then follow this path to view the video and presentation slides: *News-Members Annual General Meeting*.

Post-AGM Survey: (for attendees and non-attendees) <u>https://www.surveymonkey.com/r/Z</u> <u>HY58YW</u>

CLyDRN SURVEY...

We need your input for CLyDRN and future events: <u>https://www.surveymonkey.com/r/Y</u> <u>MP5VCM</u>

WANTED: NEW MEMBERS FOR THE EVENT PLANNING COMMITTEE

The CLyDRN Event Planning Committee is always looking for new members to join the Committee to help organize the AGM and Lyme Disease Awareness Event. If any CLyDRN members are interested in joining the Committee, please reach out to the CLyDRN Network Management Office.



CLyDRN Members Portal

If you have not yet created a user account on the CLyDRN website, please go to <u>www.clydrn.ca</u> and click on "Register" at the top. Once you register, CLyDRN Network Management Office will get an email to accept your membership. Once this occurs, you can click on "Login" and enter your email (username) and password to access the members portal. If you have a user account and have forgotten your password, simply click on "Login" and click on "Forget Your Password".

HAPPY HOLIDAYS...

Wishing you and your families all the best over the holiday season. We hope everyone is staying healthy and safe. The CLyDRN Network Management Office will be closed on December 24th and will re-open on January 3rd. Thank you for your continual support.

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CLyDRN NETWORK MANAGEMENT OFFICE

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