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SEPTEMBER 2021

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



PILLAR UPDATES

Pillar 1

DIAGNOSTICS

A consultant was hired to help develop the study design and methodology, budget, protocol, attendant documents, and complete the applications to submit to the REBs to help roll out the patient priority project in spring 2022. The consultant is leading the discussion between the scientific leads and patient and family partners to identify and determine consensus on the ultimate research goal.

Pillar 2

PREVENTION AND RISK REDUCTION

The Canadian Lyme Sentinel Network resumed surveillance activities in summer 2021 despite ongoing COVID-19 restrictions, carrying out 100 site visits across 14 sentinel regions. Data analysis was set to commence for the retrospective case-control study in summer 2021 with completion of the study by December 2021. The prospective case-control study is on hold until spring 2022. The Innovation Working Group finalized their project: cost-utility modeling and multi-criteria decision analysis for rodent-targeted interventions.

Improve prevention, diagnosis, and treatment of LD in Canada

Pillar 4

PATIENT AND COMMUNITY ENGAGEMENT, TRAINING AND KNOWLEDGE TRANSLATION

Systematic review published (https://doi.org/10.1080/14635240.2021.1920045).

Grey literature review accepted for publication. Conducted 15 virtual interviews with national healthcare practitioners. Commenced discussions on the knowledge translation porthole. Completed community stakeholder mapping exercises to inform development of the new Community Engagement Committee (CEC). Preparing the REB submission for brokered dialogue project. 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 AGM; initiating the Brokered Dialogue project (fall 2021); initiating the focus group discussions in four Canadian provinces (fall 2021); initiating the Pan-Canadian survey (summer 2022); establishing the CEC; and designing and conducting scoping review focused on Indigenous experiences/perspectives on Lyme disease.

Pillar 3

CLINICAL SCIENCE AND HEALTH SERVICE RESEARCH

The COHORT and CLYME (Biobank) studies commenced participant recruitment at the Kingston (ON) site in May 2021. 8 and 14 participants were enrolled into the COHORT and CLYME (Biobank) studies, respectively, during the pilot launch. Recruitment for the COHORT study (new participants) is now on hold until spring 2022 while the protocol is reviewed to help find ways to reduce the length of the study visits and number of tests/evaluations. The CLYME (Biobank) study continues to recruit new participants. The Lunenburg (NS) site is expected to begin recruitment for both studies in spring 2022.



COMMITTEE UPDATES

PCAC

PATIENT AND COMMUNITY ADVISORY COMMITTEE

There are 31 active members. PCAC has assisted Pillar 4 with their healthcare practitioner survey study and brokered dialogue study, assisted FC with their New Frontiers in Research Fund Letter of Intent, assisted Pillar 1 with the patient priority project, and finalized the patient compensation guidelines. PCAC was also involved in creating 2 of the 3 panel discussions for the Virtual AGM 2020.

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 clydrn@kflaph.ca.

Improve prevention, diagnosis, and treatment of LD in Canada

FC

FUNDRAISING COMMITTEE

Support of the myLyme.ca project brings to Lyme disease research in Canada new outside expertise in ecology, genomics, bioinformatics, cognition, and pain research. Successfully secured funding (\$100,000) to support a new project (genetics of range expansion in ticks and tick-borne pathogens) through the Ontario Early Researcher Award program. Supporting another application to the New Frontiers Research Fund (Exploration Grant) program. Continue 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 (robert.colautti@queensu.ca).

TAC

TRAINING ADVISORY COMMITTEE

Two webinars held in spring 2021: Modelling the Spread of Ticks and Tick-borne Pathogens & Healthcare Practitioner Perspectives on Diagnosis and Treatment. Videos and presentations have been posted on the CLyDRN website via members portal. Students and trainees also had an opportunity to present at the Lyme Disease Awareness Event held throughout May 2021. Next meeting will be in September 2021 to plan for webinars for 2021-2022 academic year. If anyone is interested in presenting to TAC, please reach out to Dr. Katie Clow (kclow@uoguelph.ca).



RESEARCH ARTICLES, 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. https://doi.org/10.1080/14635240.2021.1920045

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.

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.

LYME CARDITIS

Article: Yeung, C., Mendoza, I., Eduardo Echeverria, L. & Baranchuk, A. Chagas' cardiomyopathy and Lyme carditis: Lessons learned from two infectious diseases affecting the heart. Trends Cardiovasc Med. 2021 May; 31(4): 233-239.

https://doi.org/10.1016/j.tcm.2020.04.004

Article: Franco-Avecilla, D., Yeung, C. & Baranchuk, A. Lyme carditis presenting with an atypical rash. CMAJ May 25, 2020 192 (21) E584.

https://doi.org/10.1503/cmaj.191660

Article: Yeung, C. & Baranchuk, A. Diagnosis and Treatment of Lyme Carditis: JACC Review Topic of the Week. J Am Coll Cardiol. 2019 Feb 19; 73 (6): 717-726.

https://doi.org/10.1016/j.jacc.2018.11.035

Article: Yeung, C., Al-Turki, M. & Baranchuk The Value of the Surface ECG for the Diagnosis and Management of Lyme Carditis: A Case Report. Curr Cardiol Rev. 2021; 17(1): 5-9.

https://doi.org/10.2174/1573403X1666620031210 1751

Article: Maxwell, N., Dryer, M.M., Baranchuk, A. & Vinocur, J.M. Phase 4 block of the right bundle branch suggesting His-Purkinje system involvement in Lyme carditis. HeartRhythm Case Rep. 2021 Feb; 7(2): 112-116.

https://doi.org/10.1016/j.hrcr.2020.11.017

Interview: How to diagnosis if Lyme disease is affecting the heart and how best to treat it: https://www.lymedisease.org/cardiologist-baranchuk-lyme-carditis/

Book: The NET-Heart Book: Neglected Tropical Diseases and other Infectious Diseases affecting the Heart: https://www.elsevier.com/books/neglected-tropical-diseases-and-other-infectious-diseases-affecting-the-heart/saldarriaga/978-0-323-91122-1



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: https://lymetreatmentfoundation.org/research-grants.

For additional information, please email: info@lymetreatmentfoundation.org.

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.

SAVE THE DATE...Virtual AGM 2021

This year's half-day virtual Annual General Meeting (AGM) will be held on **Wednesday**, **November 10**, **2021** (**12-4 pm EST**). The program and meeting link will be circulated closer to the event. A meeting evite has been sent to all CLyDRN members who are on the Network's distribution list to hold the date in your calendars.

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 www.clydrn.ca 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".

TAC Webinars

To access the Training Advisory Committee (TAC) webinars (videos and presentations), please go to www.clydrn.ca and click "Login" at the top. Enter your email (username) and password and then follow this path to view the video and presentation slides: Resources-Committees-Training. There are six videos to watch: Tick Biology and Identification 101, Patient Engagement, Tools for Bioinformatics, Public Health Data Access and Use, Modelling the Spread of Ticks and Tick-borne Pathogens & Healthcare Practitioner Perspectives on Diagnosis and Treatment.

AGM and Lyme Disease Awareness Event Videos

To access the 2020 AGM video, please go to www.clydrn.ca 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-2020 Members Annual General Meeting.

To access the live presentations held at the Lyme Disease Awareness Event in May 2021, please go to www.clydrn.ca 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-News Network Update.

CLyDRN NETWORK MANAGEMENT OFFICE

Veronica Harris-McAllister Network Manager

E: Veronica.Harris-McAllister@kflaph.ca

T: 613-549-1232, ext. 1601 or Toll-Free: 1-800-267-7875

CLyDRN Members Survey

We need your input:

https://www.surveymonkey.com
/r/YMP5VCM

