

An Update from the Canadian Lyme Consortium

Hello Fellow Lyme Community Members,

Researchers in the Canadian Lyme Consortium (CLC) have been asked by some members of the community for an assessment of the “new” Canadian Institute of Health Research (CIHR) Lyme network grants and for an update on the CLC structure. We felt it was important to let all of you know what the recent changes to the Lyme funding process by the CIHR mean and, at the same time, it gives us an opportunity to update everyone on the Canadian Lyme Consortium.

As you may know, there are two national Lyme disease research networks in Canada. One is the CLC. The other is the Queen’s Lyme Research Network (QLRN), which has now morphed into the Lyme Research Network (LRN). The CLC enshrines an equal partnership between Lyme patients, researchers and health care providers at every stage of research. The LRN, headed by Dr. Kieran Moore and Dr. Tara Moriarty, appears to include many of the of the former QLRN membership, which includes members of the Association of Medical Microbiologists and Infectious Disease (AMMI) of Canada, the Public Health Agency of Canada (PHAC) and provincial public health employees.

Canadian Lyme Research “Politics” – Recap

- 2017 federal Lyme disease framework set aside \$4 million for Lyme research.
- This was given to the CIHR to disperse. CIHR decided to use the funds to support the formation of just ***one*** Lyme research network in Canada rather than directly funding research.
- The CLC, in partnership with patient groups as represented by CanLyme and the G. Magnotta Foundation, submitted a proposal for 1 of the two pre-application planning grants each worth \$30k last summer. There were only 2 applications for the two grants – one from us at the CLC and one from the QLRN. QLRN received one of the \$30k grants. The CLC’s proposal was criticized because patients were involved as partners and the application was deemed unworthy of funding. The rejection of our application is in violation of CIHR’s policy on patient engagement. No opportunity for appeal or discussion was permitted.
- Once it was known the CIHR had turned down our application, the full membership of the CLC decided to boycott the CIHR funding processes. Instead, we will pursue other funding opportunities that are focused on ethical and transparent process and strong science.

- Over the past few months, the LRN leads have been actively and repeatedly contacting CLC researchers asking that they join the LRN and asking patient advocacy leaders for endorsement of the LRN application. These offers have been unanimously, and repeatedly, rejected by the CLC and the heads of Lyme advocacy groups across Canada as not being in the best interests of patients.

CIHR Announced Changes to the Grant Application Processes

In a surprise move, on February 12th, CIHR cancelled the initial funding competition and restarted it allowing for a three-month extension on the application deadline.

After several attempts to engage CIHR in discussion, we have been able to obtain enough information to determine that the “new” CIHR competition is not significantly different from the old one. While the verbiage around the new proposal sounds good, words are cheap and, unfortunately, there is no substantive change in this new proposal. It is simply a deadline extension. One possible explanation for the extension of the deadline is that it will give the LRN more time to get patient endorsement.

CLC Position – We Continue to Boycott the CIHR Process

As a result, the members of the CLC see no reason to change our position. We are continuing to recommend boycotting this CIHR competition. The advantages of doing so are:

- That we do not endorse a process that is not in the best interests of patients, of clinicians treating patients, or researchers wanting to do unbiased research on Lyme disease. In this way, we do not lose leverage, moral integrity or scientific independence.
- That we can thereby maintain our model of patient-research-clinician engagement at all levels for all projects (more on this below). We will do meaningful science – we can investigate questions that matter to patients and matter to the health care professionals who treat patients.
- That we will be free to pursue other more science-friendly research opportunities.
- That we retain the right to lodge a protest about the previous grant not being awarded and be able to engage in a conversation directly with those at a senior level in CIHR.
- That the CLC is not forced to be part of a singular national network that has been hostile to the lived experiences of chronic Lyme patients and modern tick-borne disease science research.

If the CLC does not boycott the CIHR process, we would be forced to merge with the LRN. The key problems in merging with the LRN are:

- There is no mechanism for oversight of this funding. Once the funds go to the project leads, there appear to be no safeguards that the money would be used for projects of concern to patients. Again, they can say whatever they want about patient engagement, but there is no oversight in the process to make sure the words translate into action.
- The patient engagement model proposed by the LRN follows the SPOR (Strategy for Patient-Oriented Research) process. This process operates parallel to the main decision-making process and serves primarily as a mechanism for “experts” to tell patients what they think not vice versa. This is not a model that is acceptable to the CLC researcher, patient or physician partners.
- The CLC is committed to respectful relationships between patients, researchers and clinicians while the LRN has a history of disrespectful interactions and intolerance for new ideas. These approaches are incompatible.
- The proposed CIHR structure promotes poor science. By giving the funding to a network rather than to specific projects, it shelters research projects from peer review – funds will be disbursed based on internal decision-making processes which are not transparent or accessible.

From our perspective, the disadvantages of buy-in far outweigh any advantages. Instead, the science core of the CLC wishes to continue to focus on moving forward with a true patient-researcher-clinical equal partnership for Lyme research.

CLC Vision – A New Lyme Partnership

The CLC is committed to honouring a true partnership between Lyme patients, researchers and treating clinicians. This will mean that all of these partners will be involved in every project from the start – choosing projects, refining the question to be asked, finding resources, performing the study, conveying the results back to their respective communities.

In order to do this, the CLC will establish a (protected) membership list/database where people can register themselves and offer their expertise for research projects. This goes far beyond a patient registry where people sign up to obtain information or enroll as potential study subjects. We will be doing as well (and of course, individuals should seek out any clinical research opportunities that meet their needs) but this registry is separate from offering engagement as a research partner. An example of how the CLC partner database

will work is that should you be someone who likes watching birds and you want to participate in a study on how birds move ticks, you could volunteer your expertise.

The other important component of our research will be an “idea hatchery”. In a password-protected space on the upcoming CLC website, people will be able to propose research topics/ideas. Others will be able to comment on those ideas. Once an idea accumulates both enough interest along with the critical requirement of engagement of at least 1 patient, 1 researcher and 1 clinician member – one or more of whom is willing to be the project lead(s) – the idea is moved into the implementation phase where resources are acquired and the project initiated.

These features of the CLC model are unique in Lyme research and new in any type of biomedical research. The energy and synergy of people with different backgrounds working to a common goal fosters innovation and disrupts the status quo. (This is called [the Medici effect](#) after the Medici princes who fueled the Renaissance by bringing together diverse experts. If you want to see how the Medici effect has worked in forensic science, check out it out [here](#) – communication and positive disruptive change.)

What's Next?

We feel that this model will allow the CLC to transparently meet our goals of providing the highest calibre research in ways that reflect a true partnership between patients-researchers-clinicians. We are asking for your support and patience. We are in the process of engineering a revolution in how health care research is conducted. This takes a fair bit of work and time. It is important that we all work together towards ensuring this inclusive way of doing Lyme research comes to fruition. The status quo has served no one well. We are forging a new path that will deliver a better understanding of tick-borne diseases and bring about the much-needed improvements in diagnostics and treatments. The CLC is committed to doing things differently and we hope you will join with us and support us in our endeavours.

Let's go change the world!

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Melanie Wills, Ph.D., University of Guelph, Director G. Magnotta laboratory
Janet Sperling, University of Alberta
Jim Wilson, Canadian Lyme Disease Foundation
Jennifer Kravis and Sue Faber, LymeHope

On behalf of The Canadian Lyme Consortium and with thanks and great appreciation for those who assisted with the editing of earlier drafts of this letter and those who suggested we send out this update in the first place.