

CLL Canada UPDATE - ISSUE 28

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**1. A Word from the CLL Canada Board Chair**

COVID is now yesterday’s news, leaving people with CLL wondering how to protect themselves. All of us are immune compromised to some degree, but we are not alone. It is estimated that 3% of the Canadian population lives with a dysfunctional immune system due to an organ transplant, kidney disease, HIV, cancer, and a number of other conditions.

Faced with this situation, patient groups are mobilizing to bring the situation of the immune compromised (IC) to the attention of decision makers, including these initiatives in which CLL Canada has participated:

- The CLL Advocates Network has published a paper on the immune-related challenges facing people with CLL, available [here](#).
- A Patient Action Group has been formed in Canada which has been meeting since last year. A position paper is being prepared.
- Recently a number of patient groups, mainly European, met in Barcelona to discuss how to collaborate on this issue of common concern. Participants agreed to work on a call-to-action document on which to base future advocacy.

You will note the communality in each of these initiatives; they are all focused on establishing a portrait of the challenges faced by the IC.

Immune dysfunction is a condition that cuts across the usual categories of diseases or organs by which health care is organized. The first step we need to take as advocates is to break down these disease silos so that all those involved – health professionals, policy-makers, patient advocates – realize they have a common concern.

To become visible and gain recognition, we need to be clear on who we are and what we need. What are the health conditions that result in immune dysfunction? What are the common challenges and unmet needs of IC people? What should be done and by whom?

These questions need to be answered taking a wholistic perspective, encompassing the impacts on the whole person. Vulnerable people who remain isolated or limit their social contacts can suffer from a reduced quality of life as well as considerable emotional and psychological distress.

Those who are required to return to their workplace may have to reveal health issues to their employer to justify protective measures, which may have an impact on their career. These and other psychosocial issues need to be addressed.

To quote the conclusion the CLL Advocates Network paper referred to above:

*Immune challenges impact outcomes for people living with CLL and have a significant impact on quality of life. Areas for improving the quality of life – and reducing mortality – for people with CLL facing immune challenges largely fall into three distinct categories. These are: the need for greater research and evidence base; further knowledge and treatment options for HCPs to manage people with CLL; and greater support and range of information and resources for patients to feel empowered.*

The three initiatives described in this article have been made possible by the financial support of Astra Zeneca.

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We hope that you will find our eBulletin a useful benefit from a club that none of us wanted to join. Send your comments and suggestions to [cllcanada.org@gmail.com](mailto:cllcanada.org@gmail.com)

*Please note that the information in this eBulletin was current as of the date it was published. In science and medicine, information is constantly changing and may become out-of-date as new data emerge.*

## 2. Looking for a Clinical Trial?

The Clinical Trials Navigator (CTN) is a service that will search for clinical trials for Canadian cancer patients. The CTN was set up as part of a research study on participation in clinical trials. To use the service, you must consent to participation in the study.

To request a search for clinical trials, you complete a two-part questionnaire. In the first, demographic, personal and individual cancer information is gathered. Personal information questions are optional and will not impact the search for potential trials. The second part gathers information on your specific cancer, including dates of diagnosis, when staged, and previous treatment start and end dates, if applicable.

The information submitted in the questionnaire is reviewed by the research team, who will then contact you with the results of their search. If a trial is found, a clinical report will be included for you to use in discussions with your oncology team.

The Clinical Trials Navigator can be found [here](#).

### **Additional resources on clinical trials:**

The worldwide reference site for clinical trials is [ClinicalTrials.gov](https://clinicaltrials.gov).

[CISCRP](#) is a US based site that will search for clinical trials in Canada.

To search for clinical trials in Quebec access the [OncoQuebec website](#), available in English and French.

### **For our United States readers:**

Listen to a 25-minute podcast about clinical trials with Neena Kennedy, BSN, RN, OCN from the Leukemia & Lymphoma Society in the USA [here](#).

If you or someone you know is looking for clinical trial support in the USA, you can access the [Clinical Trial Support Centre](#).

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## 3. Be Your Own Advocate: A Lymphoma Canada Webinar

This 30-minute webinar is based on the premise that the more educated you and your caregivers are, the more you are able to ask questions and fully partner with your doctor(s) as you navigate through your CLL journey.

During this webinar Sarah Eisinga, Manager of Patient Programs, Research, and Advocacy at Lymphoma Canada, walks through the Lymphoma Canada website to

share information and patient resources contained on the site and where you can find them.

Whether you are newly diagnosed, or further along in your journey, this site provides a lot of relevant, factual, and Canadian-based content that you and your caregivers can rely on to learn more about CLL, its treatment, and resources available. You can watch the webinar [here](#).

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#### **4. CLL Canada News**

In collaboration with Lymphoma Canada, our usual partners, we submitted a brief to CADTH and INESSS in support of the combination of Ibrutinib and Venetoclax as a first line CLL treatment. These two agencies make recommendations to provincial health ministries (INESSS for Quebec only) regarding which treatment they should provide to patients.

In early June, the CLL Board of Directors met in Toronto, the first in-person board meeting in over four years! In addition to being a valuable team building opportunity for board members, some important decisions were made. Our thanks to Beigene whose support made this meeting possible.

We decided that the next CLL Live conference for patients will be held in April of 2025 in Niagara Falls, Ontario. While it will be an in-person conference, we are looking at the possibility of adding an online or hybrid option. A planning committee has been formed to determine the agenda and the speakers

Since 2007, CLL Live conferences have provided people with CLL and their care partners with an opportunity to learn about living with CLL from both experts and fellow patients. You can find videos from previous conferences on our website [here](#).

The second major item of business at the June board meeting was the incorporation of CLL Canada. Up until now, CLL Canada has been a collaborative with no legal status. CLL Canada will now be a registered not-for-profit corporation with the legal status that such a format provides.

As usual we have continued to bring the CLL patient voice to health stakeholders in a variety of settings.

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#### **5. LLSC Webinar: The Causes of Blood Cancers – What we Know**

When diagnosed with a blood cancer, the first thing many of us wonder is what caused it. Dr. John Dick's research has focused on just that question.

In this one-hour webinar, he shares how the development of cancer within the body is a complex process, and he speaks to the research that has been conducted over the past several decades to understand it.

Dr. Dick explains how blood cells are formed at a cellular level, and how mutations in different parts of the process can ultimately leave us with a blood cancer diagnosis. He also speaks to the importance and role of blood stem cells, and the impact of targeted treatments as compared to traditional chemotherapy.

The webinar sheds light on the future focus of finding treatments that impact blood cells at the precancerous stage to prevent a blood cancer from developing – which gives much hope for the future. You can watch the full webinar and read the transcript [here](#).

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## 6. Mysterious and Painful Insect bites

People with CLL are particularly susceptible to insect bites, another consequence of a dysfunctional immune system. Recently two CLL Canada board members had an instructive exchange on this topic.

*Frequently I sit in my backyard listening to music and without realizing, I get insect bites which show up the following days as the most itchy sores that I have experienced. They leave dark red welts which last for days.*

To which another board member responded:

*I experienced the same thing and traced it: It's European Fire Ants. They're very small--unnoticeable--and have only recently moved into Canada. They're an invasive species that came over from Europe to Southern USA and have been steadily moving north for years. They only hit British Columbia around 2009, New Brunswick around 2010, Southern Ontario around 2012 and have only really become a nuisance in the way you describe in recent years. Their bites are exactly as you describe. I've received many! Frustratingly, they are very hard to deal with.*

*I check my chairs and furniture every time I sit down now. They're very hard to see. Tiny! But it has saved me a few times now.*

For more information, here are two articles about fire ants by the [CBC](#) and the [National Collaborating Centre for Environmental Health](#).

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## 7. Book Review: *How Doctor's Think* by Jerome Groopman, MD

Have you ever been to a doctor's appointment, ready to explain what ails you in the greatest detail, only to have the doctor cut you off after just a few minutes? How can he or she come to a conclusion without knowing all the details?

This book is about what goes on in a doctor's mind as she or he meets a patient. It is about diagnosis, determining what is wrong, and what should be done about it. The book details the shortcuts doctors use to come to a rapid diagnosis and the

pitfalls of this approach. It also describes rare conditions for which establishing a diagnosis is very difficult.

The author explains the problems encountered in establishing an accurate diagnosis in a variety of settings: emergency medicine, cancer care, rare diseases, surgery, and radiology to name a few. The author, a doctor himself, relates his own experience as a patient with a difficult to treat injury.

The focus on difficult cases and missed diagnoses is effective in explaining how diagnoses are made and what can go wrong. Understanding the causes of medical errors and the limit of medical science helps us as patients to evaluate the care we are receiving. On the other hand, it can give the impression that diagnostic mistakes are more common than they really are.

This is a well-written book which will be of interest to all patients. It captures the reader's attention with numerous stories from the front lines of medical care and useful insights into how medicine is actually practiced in the clinic. For patients, the book will serve as a resource for navigating the health care system, especially when they feel their needs are not being met.