

CLL Canada UPDATE - ISSUE 32

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1. A Word from the CLL Canada Board Chair

Recent advances reflect a hopeful trend in the 'world of CLL'. When we organized the first CLL Live patient/caregiver conference in 2007, the subject of treatment dominated the conference agenda. As targeted therapies such as the BTK and BCL2 inhibitors have become available, the theme of living well with CLL has become increasingly prominent in the four subsequent conferences.

This edition of our eBulletin reflects this shift with articles on strategies to avoid contracting COVID and the use of immunoglobulins to reduce infection risk. Reading the interview with Dr. Kanti Rai will give you an idea of how far we have come in the treatment of CLL.

Unfortunately, this progress has not been uniform across the globe. In low and middle income countries access to targeted therapies is limited, if not impossible. This concern was highlighted in two international patient organization conferences attended by CLL Canada board members this fall. The sharing of knowledge and experience at these conferences is useful to all of us involved in patient advocacy. It also reminds us of our good fortune to have the access we do to targeted therapies.

Ensuring access to treatments which enable people with CLL to live longer remains a central concern of CLL Canada. With the success of targeted therapies, living well during those additional years and coping with a compromised immune system are themes that have gained in importance in our work. We will continue to explore all

these aspects of living with CLL on our website, in our bulletin and at the [CLL Live 2025 conference](#).

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

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 In science and medicine, information is constantly changing and may become out-of-date as new data emerges.

2. A Giant in Hematology: An Interview with Dr. K. R. Rai

For all the history buffs out there with a keen interest in the evolution of hematology, this exclusive interview with Dr. Kanti R. Rai takes you on a fascinating journey through his illustrious career. A pioneer in chronic lymphocytic leukemia (CLL), Dr. Rai's work has shaped the field of clinical hematology and advanced treatment for leukemia patients around the world. Learn about his path from pediatrics in rural India to becoming one of the foremost experts in leukemia, his mentorship of future doctors, and the pivotal research that has defined his career. Read the full article [here](#).

3. COVID-19 Protection: Key Insights for People with CLL

How do people with weakened immunity safely navigate this world where the COVID-19 virus is still circulating, but everybody 'acts as if' it has disappeared? Here are some strategies that people with CLL whose immune system is impaired can keep COVID at bay.

Using **nasal sprays or gels** is a simple and inexpensive strategy to reduce the duration of illness from respiratory diseases, including COVID-19. A UK study found that using saline or gel nasal sprays at the first sign of illness significantly shortened the duration of symptoms. This easy-to-implement intervention carries little to no risk, making it an excellent option for people with CLL who are trying to minimize the impact of respiratory infections. See the full study [here](#).

The CLL Society hosted a webinar, "**COVID-19 in 2024: Recommendations and Strategies for Those with CLL and SLL**". Dr. Mustafa, University of Rochester, reviewed the ongoing risks of COVID-19 for people with CLL, including the higher likelihood of hospitalization and severe outcomes. The webinar spoke to preventative strategies such as getting vaccinated and masking in high-risk settings, preparing an [action plan](#) in case of a positive COVID-19 test, and

medications that can be taken to reduce symptoms. To watch the full webinar, click [here](#).

The INFORM Study from the UK analyzed **the impact of the Omicron variant of COVID-19 on immunocompromised individuals**, including those with CLL, comparing them to the general population. The study found that while immunocompromised individuals made up just 3.9% of the study population, they accounted for 22% of hospitalizations, 28% of ICU admissions, and 24% of deaths due to COVID-19. Given immunocompromised individuals often experience impaired immune responses to vaccines, it also emphasized the importance of staying up to date with boosters. The full study can be found [here](#).

Another resource, the [Canadian Respiratory Virus Surveillance Report](#), provides a weekly overview of key trends in the activity of respiratory viruses, such as influenza (flu), COVID-19 and respiratory syncytial virus (RSV) in Canada which can further help assess the risk of exposure. By staying informed on the risks, and proactive in the use of preventive and mitigating strategies, we can better safeguard ourselves in these ongoing challenging times.

4. CLL Canada News

The 6th CLL Live conference scheduled for April 24-26, 2025 continues to be the focus of our attention. Registration will open in January 2025, until then information on the conference is available on our [website](#).

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

5. Reducing Infection Risk Through Immunoglobulin Replacement Therapy

Living with chronic lymphocytic leukemia (CLL) can make us more vulnerable to infections since we have a weakened immune system. A condition called **hypogammaglobulinemia** - a reduction in the antibodies that help us fight off viruses and bacteria - is common in people with CLL. Fortunately, **immunoglobulin replacement therapy (IgRT)**, which provides patients with antibodies from healthy donors, has been shown to reduce the risk of infection.

A recent study conducted by Dr. Jacob Soumerai and colleagues at Massachusetts General Hospital looked at how IgRT was being used to treat patients with CLL, finding that:

- Over half the CLL patients experienced an infection at some point.
- Approximately **one-third of patients** had not had their IgG levels tested.

- Of those who were tested, one-third of patients had low antibody levels, making them more susceptible to infections.
- Only 6% of patients received IgRT.
- Patients who received IgRT showed fewer and less severe infections, and reduced use of antibiotics. (See the full CLL Society article [here](#).)

Overall, this study highlights the need for increased **IgG testing** to identify patients who might benefit from IgRT, all the more so if you suffer from recurring infections from which it takes a long time to recover.

What can you do? Ask your healthcare provider about testing your immunoglobulin levels. A simple blood test can help identify if you're at risk and whether IgRT could help protect you from infections.

6. Studies Recruiting CLL Patients

The impacts of having to travel for treatment

Have you needed to travel outside your home town or city for blood cancer treatment in the past 5 years, or cared for a loved one (adult) who has? If so, the Leukemia and Lymphoma Society of Canada wants to know [what your experience was like](#).

This study's results will increase awareness of the impacts of travel to treatment as a topic for discussion across Canada, including with authorities who make decisions on public funding for cancer drugs.

EN Survey: <https://www.surveymonkey.com/r/WVBBWJC>

FR Survey: <https://www.surveymonkey.com/r/SVG2ZVW>

How individuals living with and beyond cancer could increase their physical activity levels.

This study aims to test a supervised exercise program, combined with either exercise or behavioural counselling, to help participants increase their physical activity levels. The study is all done virtually in the comfort of your own home and no in-person study visits are required.

Participants receive an exercise program for 6 months with a qualified exercise professional. Any cancer patient or survivor across Canada can participate.

If you have questions there is an [information video](#) to watch. Contact the study researchers by email: exercise.oncology@utoronto.ca or phone 416-946-5856 if interested in participating.

The experience of caregivers to patients taking immune globulins

This study will explore caregiver experiences with patients who have rare diseases treated by plasma-derived medicinal products (PDMPs) such as immune globulin (Ig) to understand how their unique perspectives may help inform policy changes.

The study will involve the completion of a demographic questionnaire (approximately 10 minutes) and a one-on-one qualitative interview (approximately 1 hour).

Interviews will explore experiences of the caregiving challenge of caring for a patient with a rare disease, and perspectives on treatment options and access.

Those interested in participating can contact yunting.chu@mail.utoronto.ca for further information.