

CLL Canada UPDATE - ISSUE 29

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1. A Word from the CLL Canada Board Chair

It’s called evidence-based advocacy and you can be a part of it by completing the [CLL Advocates Network 2023 Global Leukemia Patient and Carer Survey](#). The aim of the survey is to understand the important issues, experiences, and needs of CLL patients and to see how things are changing over time.

Some of you will recall that this is not the first time we are asking you to complete a survey of CLL patients. It won’t be the last either, since these surveys of the patient experience have become an important tool for patient advocacy groups. Not just in Canada, but around the world.

For instance, CLL Canada is one of many patient groups that have long advocated for the provision of information on CLL to patients at the time of diagnosis. With survey data we now have solid evidence that:

- Less than half (47%) of those diagnosed with CLL were offered written information regarding their diagnosis; over 70% of those who were not, would have liked to have some.
- While most (75%) of patients understood at least some of the explanation of their diagnosis, only a third fully understood it.

The surveys provide us with a better understanding of patient needs. By way of example, the CLL Advocates Network is creating a clinical trials platform in response to the need expressed in the 2021 survey for better access to information on clinical trials.

Now that we have data, you might well ask why a new survey is required? It is imperative to have up to date information because the situation can change over time. The pandemic has shown us we need to know how aware patients are of their vulnerability to infection and how well clinicians are helping them live with their compromised immune system. Furthermore, it is too easy for those who do not want to hear our message to dismiss our advocacy by claiming the data as being out of date.

This is an international survey, and the results are used by patient groups in countries as diverse as Brazil and the Philippines in their discussions with government authorities, health professionals and pharmaceutical companies on patient needs and how best to meet them.

The findings of the 2021 survey, which highlighted the lower quality of care in low- and middle-income countries, were instrumental in the initiation of a joint project between patient groups and CLL specialists to better inform health professionals in those countries about CLL.

Please complete the CLLAN survey of the CLL patient experience before the end of November by [clicking here](#) or using the QR code.



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. Treatment News: Zanubrutinib Soon to Become Available to Canadians

Some good news for CLL patients: Zanubrutinib is moving through the Canadian drug approval process faster than expected. An agreement on the price of the treatment was recently reached between the manufacturer and provincial governments.

In the normal course of events, we can expect that by spring 2024, most provincial governments will have provided access to Zanubrutinib for patients not covered by

private drug insurance plans. Patients enrolled in these plans had access to Zanubrutinib since it obtained Health Canada's approval last spring.

Beigene, the manufacturer of Zanubrutinib, runs a patient support program which can answer questions and assist with access issues. Contact information is available in the MyBeigene section of the [Patients page of the Beigene website](#).

3. To Trust or Not to Trust? The Use of ChatGPT to Answer Medical Questions

A recent study was conducted to evaluate the accuracy of the information ChatGPT provided in answer to medical questions, and to assess the credibility of the reference sources that were cited.

Powered by its use of large amounts of data, ChatGPT is an artificial intelligence chatbot that is able to perform many language-related functions, including answering questions. Millions of people have used the app since it launched in November 2022, and many could be using the app to pose questions of a medical nature.

In the answers to the 17 questions that were asked, ChatGPT made 5 major factual errors and 7 minor ones. Of the 59 references that ChatGPT cited, 41 (69%) were fabricated, although they appeared real.

This raises the important question of whether ChatGPT can be trusted as a valid source for medical information. For additional details, read the full study [here](#) and a newspaper article on the study [here](#) in French.

4. CLL Canada News

CLL Canada Board Chair Raymond Vles was interviewed for an [article on CLL](#) that appeared in a special Blood Health section published in Maclean's magazine.

Raymond also participated in a panel discussion on health literacy at the Global Lymphoma Summit, where he made a presentation on our CLL Information and Resource Centre.

CLL Canada endorsed the call to action published by the newly formed [International Immunocompromised Advocacy Network](#).

CLL Canada also joined Lymphoma Canada in making a submission in support of the combination treatment of Ibrutinib and Venetoclax (I+V) to Canada's two health technology assessment agencies¹. This combination offers the potential for long lasting remissions after a year of treatment without requiring hospital visits, unlike Ibrutinib alone which is taken indefinitely, and Venetoclax with Rituximab which requires hospital visits. I+V is an attractive option to those for whom hospital visits

are a problem because they work, are caretakers and/or live a great distance from a hospital.

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

¹INESSS for Quebec and CADTH for the rest of Canada

5. How We Can Use Our Cancer: A Patient's Perspective

This patient blog posted on curetoday.com shares an interesting perspective that we can take as members of the cancer community. Suzanne Remington notes several ways we can use our cancer diagnosis to make a positive difference for those who are battling various forms of cancer. Read the full blog [here](#) to identify ideas to not "waste our cancer".

6. COVID Update

At the October 2023 Lymphoma Canada National Conference, Dr. Versha Banerji (CancerCare Manitoba and Senior Scientist at the Research Institute in Oncology and Hematology) presented an update on COVID-19 for lymphoma and CLL patients based on real world data.

Her presentation discussed risk factors and outcomes for various groups of patients, antibody response to vaccines, and available therapies for those who contract COVID.

Some key messages were:

- The more doses of vaccines CLL patients had, the better the immune response and the effectiveness of the vaccine.
- Stopping a BTKi treatment (Ibrutinib, Acalabrutinib, Zanubrutinib) for a short period before and after vaccination will improve the response of the immune system. It is important to consult your doctor to ensure this is safe in your particular situation.

[Click here](#) to see the full presentation.

7. Paxlovid Rebound – What is it and What Does it Mean for CLL Patients?

Paxlovid is one antiviral treatment that may be available (if not contraindicated with other medication taken) for immunocompromised people, including CLL patients, who contract COVID to reduce the severity of the illness. A recent article by Dani Blum, a reporter for The New York Times, discusses 'Paxlovid rebound' based on interviews with several doctors.

Paxlovid rebound refers to the return of symptoms or a positive test after the treatment has been completed, typically within a week of recovering from the virus.

It can be difficult to differentiate between rebound symptoms and those who have developed long COVID, making it hard to determine how often rebound occurs.

Research conducted reports a wide range of occurrence from 2.3% in a Pfizer clinical trial to 14% of people who took Paxlovid based on outside research. Interestingly, even those who have not taken Paxlovid can experience rebound.

Other research indicates an incidence of 1.7% (Pfizer trial) to 9% (outside research) of the return of symptoms for those who have not taken Paxlovid. It is important to note that real world data is also difficult to find since many who may have had rebound did not report it to their doctors.

The theory behind Paxlovid rebound is that this drug is so effective at suppressing COVID that a person's immune system doesn't turn on its antibody defenses following treatment the way it should, allowing the virus to return.

Advice for those who experience rebound is to assume that if you test positive again on a rapid test that you are contagious and should take the necessary precautions of isolating and masking. It is estimated that rebound can last anywhere from two to ten days (with an average of three days).

The good news is that rebound symptoms are usually milder than the original illness, and another course of Paxlovid is not typically required. However, if symptoms become severe, it is recommended to reach out to your doctor.

8. My Journey to Recovery

Editor's note: This is part one of CLL Canada board member Robert Pitter's CLL journey. It is a story of courage, resilience, and the wise use of exercise to improve one's quality of life based on two principles: 1) start small; 2) when in doubt about how much to do, do too little.

Part One: How I Started at Near Zero

"Don't worry," said the internist, "you will likely never need treatment."

I had just been diagnosed with CLL at age 51 after seeking a medical reason for six months of fatigue.

She was right, sort of. Seven years later, it turned out she was wrong; very, very wrong.

In 2016 I started treatment with Acalabrutinib and shortly after was hospitalized. Toward the end of the week, my organs began failing. In desperation, doctors switched me to CR (FCR without Fludarabine to avoid harming my failing kidneys),

my first cycle of the FCR treatment I had hoped to avoid. Subsequent tests showed I had hemophagocytic lymphohistiocytosis (HLH), a rare, life-threatening condition where the immune system attacks the body. The CR stopped the HLH, but my hospitalization lasted three more weeks.

When I finally went home, I was very weak. I needed a walker to get around. My feet tingled sharply with neuropathy (pain caused by damaged nerves). I had the strength of a bowl of Jello, struggled to get out of a chair unaided, and barely had the energy to shower myself while sitting in a chair.

Despite my weakness, I was determined to regain my strength and return to work after what I expected would be a month or two. Lacking the mental energy and motivation to come up with a detailed plan, I adopted two simple principles. One, start small, and two, when in doubt about how much to do, do too little because I could always choose to do more next time and avoid injury that might come from doing too much.

During the five months I received full FCR, I did what little I could do and very gradually built on that. Instead of keeping to a schedule, I used my energy level as a guide. When I felt I had some energy, I would get up and move. When I got tired, I rested. I rested a lot.

To say I began by walking would be an exaggeration. I leaned on furniture and walls to move through the house until I could do it unaided. After a few weeks, my first sense of progress was walking to the end of my 20-meter driveway.

Remembering that seated exercise was an option, I searched the internet for videos of chair yoga. Using my two rules, I rejected videos with movements beyond my ability and chose ones with advice to be mindful of personal limitations. My aim was to be able to complete 20 to 30 minutes of chair yoga regularly. I gave myself permission to stop when I got tired even if it was only after a few minutes.

As the chemo regime ended, I was walking for 50 minutes a few times a week. The neuropathy made walking uncomfortable on a good day but painful on most. I discovered having a partner to talk with provided a good distraction from the pain, so I invited family or friends to plod along with me. That helped a lot.

Nonetheless, as my strength and pace improved, walking became more painful. With chemo behind me, I tried cycling, another physical activity I enjoy. I began by riding twice a week for 30 minutes on flat roads or trails near my home and worked my way up to epic 90-minute rides on hilly terrain that sometimes took several days to recover from. Yes, I broke my second rule but at least I did not injure myself. Cycling put less pressure on my feet which meant less aggravation. Moving faster and needing to pay close attention to my surroundings created an even more effective distraction than a walking partner.

When fall 2017 arrived, I bought a bike trainer and moved my physical activity indoors.

I increased my cycling to 30 minutes four times a week. To make the rides more interesting, I used a virtual cycling application, Zwift, that simulates riding outdoors. I ignored Zwift's emphasis on competition but eventually tried some modified workouts and training programs determined by my energy levels.

By this time, I finally felt well enough to begin a gradual return to work. Twelve months later, my strength and stamina were almost back to pre-treatment levels, and I was working full-time. I cycled four to six hours a week and played ball hockey for two hours. But after only four months, I suffered another major CLL setback.



The wheel-on trainer I started with



The direct drive trainer I switched to

In Part Two, I share how I recovered from that and other disheartening setbacks. I will also provide some general information about managing setbacks, barriers, and motivation.