

CLL Canada UPDATE - ISSUE 30

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1. A Word from the CLL Canada Board Chair

Spring is around the corner and there are a lot of reasons to feel optimistic. In this bulletin we report some encouraging statistics on the life expectancy of CLL patients as well as progress in the approval of a time-limited treatment combining Ibrutinib and Venetoclax. We also report on a study showing that it may be possible for patients to pause their BTKi treatment for a time.

I was basking in this good news when I read an article in the Montreal-based La Presse that cast these successes in a different light. It appears that the very success of cancer treatments is increasing the demands on our already overloaded health system.

More effective treatments mean more patients surviving cancer. More patients in remission means more people doctors see for follow-up appointments and testing every three to six months or so.

Meanwhile, new patients keep arriving, adding to the numbers that must be looked after by healthcare professionals.

As so often seems to happen in life, solving one problem has created another. A better problem to have, no doubt, but as patients, we need to consider how it will affect our care.

Will hematologists see only those patients whose CLL is serious enough to require expert professional attention? Will those of us in stable remissions or in watch and wait be followed by a family doctor or a nurse practitioner? Will patients be asked to take a more active role in monitoring their health, perhaps assisted by artificial intelligence?

We don't have answers to these questions, but as our health system creaks and groans under the weight of the demands placed upon it, perhaps we should start thinking about them.

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 In science and medicine, information is constantly changing and may become out-of-date as new data emerges.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. Can Ibrutinib be Safely Paused?

A recent study using 172 participants from the FLAIR trial out of the UK is the first of its kind that looks at what happens when Ibrutinib treatment is stopped in patients after six years of successful treatment. Currently, those treated with a BTK inhibitor such as Ibrutinib are kept on continuous treatment until it stops working or until they develop side effects serious enough to discontinue treatment.

In most of the patients who stopped taking Ibrutinib after six years of treatment, the levels of residual (remaining) disease either decreased or stayed the same for 6 to 12 months after stopping treatment.

In those patients who stopped treatment with Ibrutinib due to side effects, the median progression free survival (PFS) was about two years from the time treatment was discontinued, meaning their CLL was stable for that period.

These results show that BTKi therapy may not have to be a "forever drug". More importantly, they raise the possibility of reducing the incidence of resistance or intolerance by taking patients off treatment when their CLL is controlled and restarting it when their disease progresses.

More research is required to develop this kind of intermittent treatment strategy to answer questions such as which patients would benefit, when to stop treatment and whether a BTKi would still be effective when the treatment was restarted.

For a more detailed review of the study results and a short video of Dr. Brian Koffman of the CLL Society presenting a summary of the results, click [here](#).

3. High Survival Rates for Canadian CLL Patients

There is good news for Canadian patients with CLL. The survival for those diagnosed in 2015-2017 with Chronic Lymphocytic Leukemia is projected to be 86% five years from diagnosis, and 73% at the ten-year mark. This data comes from the [2023 Canadian Cancer Statistics Dashboard](#).

Also noteworthy is that of the 28 types of cancers analyzed, CLL has the fourth best survival rate at five years and the fifth best at ten years.

We can be optimistic that these survival statistics will improve in the years to come due to the advent of targeted therapies (Ibrutinib, Acalabrutinib, Venetoclax, etc.) that are more effective than the treatments used in the reference period for these projections.

To see more clearly predicted survival for CLL patients, click on "Filter" at the top of the chart and use the check boxes to select CLL data alone and to see the data for men and women separately; then click on "Apply" in the bottom right corner.

4. CLL Canada News

We've received a number of emails inquiring about the next CLL Live conference. We are pleased to announce that CLL Canada will be hosting its 6th CLL Live conference next year, starting the evening of April 23 to April 25, 2025 in Niagara Falls, Ontario.

The 2025 CLL Live conference will feature CLL expert clinicians and researchers speaking about all aspects of life with CLL. It will also provide people with CLL and their care partners the opportunity to connect with fellow patients. You can find videos from previous conferences on our website [here](#).

CLL Canada submitted a brief to CADTH, Canada's Drug and Health Technology Agency, pointing out some issues with a proposed funding

algorithm. This is a guideline intended for use by provincial governments to determine the sequence treatments to fund for first line, second line, etc. We pointed out that some treatment options required by patients in particular circumstances were missing.

Peter Haggert, a CLL Canada board member, was nominated to the Steering Committee of the [CLL Advocates Network](#), an international coalition of CLL patient advocacy organisations. Congratulations Peter!

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

5. Ibrutinib + Venetoclax Combination Recommended with Conditions

The combination of Ibrutinib and Venetoclax (I+V) came one step closer to being available as a first line treatment to CLL patients. Canada's health technology agencies have recommended that provincial governments fund this treatment, but with conditions. CLL Canada and Lymphoma Canada had made a joint submission to the agencies on the patient perspective regarding this combination.

The I+V combination is now at the next step in Canada's long and tortuous drug approval process: the negotiation of a treatment price between the manufacturer and the pan-Canadian Pharmaceutical Alliance (pCPA), whose members are the federal and provincial governments in Canada.

CLL Canada is writing to the pCPA to point out that I+V is a win-win treatment option for both patients and government payers. I+V provides a one-year, fixed duration treatment option for some patients who would currently take a BTKi (Acalabrutinib, etc.) indefinitely or until forced to discontinue due to side effects or disease progression. For patients who achieve the expected two+ years of remission, the overall cost of a fixed duration I+V treatment will be less than a BTKi monotherapy regime.

New I+V Clinical Trial Results

Recent data from the Flair trial, a large-scale clinical trial in the UK shows promise for the use of I+V as a first line treatment for patients with CLL. Our friends at UK CLL Support recently held a webinar on the Flair trial, which can be seen [here](#).

Some key findings of the study include:

- I+V was superior to FCR for progression-free survival (PFS) - the length of time the CLL does not return, and overall survival (OS).
- I+V compared to Ibrutinib monotherapy showed the superiority in achieving undetectable MRD (cancer cells not detected in the blood and bone marrow).
- No new safety concerns were found with I+V.

FCR was almost as effective as I+V in patients with mutated IGHV status, both in terms of PFS and OS. This will reassure those of us who feel they missed out on targeted therapies, having been treated with FCR before they became available.

The results of this trial support the use of I+V as an effective treatment that we hope will soon be funded across Canada.

6. New COVID-19 Resource for Blood Cancer Patients

The CLL Advocates Network (CLLAN) has just announced the release of a resource developed by the International COVID-19 Blood Cancer Coalition (ICBCC) for those with blood cancers. This booklet, entitled "*Navigating a Post-Pandemic World: A Guide for Immunocompromised Blood Cancer Patients*", provides practical ideas and guidance for how to reduce your chances of contracting COVID-19 and general advice on managing symptoms if you do get it. You can view it online [here](#), with the option of downloading it as a 17-page PDF booklet. To read more about the formation of ICBCC and how the guide was developed, see the latest CLLAN newsletter [here](#), and scroll to the second article to see the announcement of the guide.

7. Opportunities for Patient Input

Outlined below are some current opportunities for people with CLL to share thoughts and experiences and have your voice heard.

Lymphoma Coalition's 2024 Global Patient Survey:

The Lymphoma Coalition global survey of Lymphoma and CLL patients seeks to understand the patient experience and the impact of treatment and care. Member organizations around the world use survey results at a national level to ensure the patient voice is heard and to drive their planning, actions, and

support. The Coalition itself uses the data to advocate for patients in international medical and health policy conferences.

The survey is available in 20 languages, and takes about 30 minutes for patients, and 20 minutes for caregivers to complete. The survey, found [here](#), will be available for another month.

Improving Virtual Patient Care (Ontario residents only):

Researchers at the University of Toronto are looking for Ontario residents to participate in a study which aims to develop patient-centered recommendations for policymakers and leaders in Ontario to guide the future of telephone and zoom appointments in primary care.

Participants will be asked to join a 60-to-90 minute focus group about experiences with telephone and/or video appointments, patient portals, and to offer suggestions on how to improve virtual care for the future. Focus groups will occur across Ontario, primarily online.

Ontario residents who wish to participate should fill out [this short questionnaire](#). Participants will receive a gift card honorarium in recognition of their time.

Heal Canada

The primary goal of the Quality-of-Life Survey is to gather detailed information on blood cancer patient's physical, psychological, and social well-being. By understanding these aspects, the survey aims to identify areas where interventions can make a meaningful difference in their lives. This research is crucial for developing strategies that enhance patient care and support beyond the clinical treatment outcomes. The survey is in [English](#) and [French](#).

8. My Journey to Recovery, Part 2

Editor's note: This is the second and final installment of CLL Canada board member Robert Pitter's CLL journey (see note 3, below). It is a story of courage, resilience, and the wise use of exercise to improve his quality of life using two principles: 1) start small; 2) when in doubt about how much to do, do too little. He now picks up the story in 2019.

Setbacks

Despite significant advances in treatments for CLL, some of us will find ourselves being kicked by CLL or its ancillary henchmen on more than one occasion. Your CLL could be refractory, relapsed, or perhaps making you prone

to infections that completely set you back after whatever gains you feel you have made. This was true for me.

After two years of recovering from HLH¹ and FCR treatment, I resumed full-time work at age 60. Unfortunately, after only 4 months, I became seriously ill with HLH again, this time due to Richter's transformation. The prescribed treatment was R-CHOP.

Following a 4-week hospitalization, I returned home completely dispirited. I was able to walk unaided but was significantly weakened, having not fully recovered from the previous illness. I experienced many complications from R-CHOP including febrile neutropenia², shingles (a year after receiving Shingrix), and several other very unpleasant and debilitating infections.

Disheartened, frightened, and fearful, I took the same gradual approach to recovery through physical activity and exercise that I described in part 1 of my story³. I began by walking and doing seated yoga. Ten months passed before I was able to be physically active on a regular basis.

The R-CHOP had worsened the neuropathy⁴ in my feet, so I put more time into cycling and less into walking. Fourteen months into this recovery, I was able to cycle 3 to 4 hours a week for up to 1 hour at a time. I was able to do some very gentle stretching on the floor. Getting onto and off the floor was challenging but doable.

I then suffered another setback with a significant saddle pulmonary embolism⁵. Despite being told it was a serious incident, it was less difficult to deal with than my previous challenges. I was hospitalized but able to walk around unaided the day after my admission. After five days of observation, I was discharged. It only took a few weeks for me to gradually return to my 3- to 4 hour-per-week cycling regime.

¹Hemophagocytic lymphohistiocytosis (HLH), a rare, life-threatening condition where the immune system attacks the body.

²Neutropenia is an abnormally low concentration of neutrophils in the blood. Neutrophils serve as the primary defense against infections.

³ For the first part of Robert's story, see [E-Bulletin 29](#) on the CLL Canada website.

⁴ Neuropathy is nerve damage that causes weakness, numbness and pain in the hands and feet.

⁵A saddle pulmonary embolism is when a large blood clot blocks the main artery of the lungs.

Eliminating Barriers and Finding Motivation

These setbacks left me with less energy and more idle time. Drawing from research about physical activity, I understood I might regain my momentum if I eliminated excuses and found sources of intrinsic and extrinsic motivation.

For me, neither walking nor cycling was barrier free. Unable to work, I used some of my time to research and think of ways to minimize things that made being active difficult, annoying, or unpleasant:

- As mentioned in part 1, I invited family or friends to walk with me as a distraction from the painful neuropathy.
- To address discomfort when cycling, I had my bicycle properly fitted by a professional bike fitter.
- To reduce anxiety about traffic while cycling, I installed a rear light with radar technology that sends vehicle alerts to my bike computer (the radar also works with cellphones).
- To avoid the demoralizing long steep hills around my home, I drove to flatter routes nearby. Eventually I changed my bike's gearing for easier uphill riding. I considered purchasing an e-bike.

My intrinsic motivation came from wanting to regain my independence and ability to do my own self-care and home care. It can also come from activities you enjoy doing. The activity doesn't have to be sport or exercise-related per se. Self-care, cleaning house, gardening, dancing, or anything that gets you moving more vigorously and a bit out of your current comfort zone can be helpful. I chose cycling.

For extrinsic motivation I primarily relied on social connections, the most consistent factor shown by research to predict regular physical activity.

I used strategies such as:

- Establishing a habit of walking to get the mail instead of combining the 1-kilometre trek to the mailbox with other errands that required the car.
- Scheduling my mail walks to match my son's arrival at the school bus drop-off.
- Going for a walk or ride with others who are supportive.

How am I today?

It's been almost four years since the embolism and nearly five since I finished R-CHOP. I have recovered much of my strength. Getting on to and off of the floor is no longer a physical challenge. My stamina and resistance to fatigue has greatly improved. I often walk briskly for at least 20 minutes. I bike 6 to 8 hours a week. I am able to complete a 2—3 hour ride and recover overnight or in a couple days.

Never in my life have I felt I worked so hard for such slow and seemingly little gains. I have learned to appreciate every tiny advance, no matter how small. I encourage everyone to consider being physically active regardless of where you are in your own CLL journey.

Be active for yourself and do what you love with those whom you love.