



Cholangio-Hepatocellular Carcinoma Canada Newsletter

Volume 1, June 2024

Welcome!

Welcome to the first Cholangio-Hepatocellular Carcinoma Canada (CHCC) newsletter. As part of our aim to connect with patients, caregivers, and medical professionals, and to share vital information about medical advances, we are initiating a quarterly newsletter in both English and French.

Cholangio-Hepatocellular Carcinoma Canada is now a registered charity! Our Charitable Registration Number is 709631014 RR 0001

Cholangiocarcinoma Foundation (CCF) Conference held yearly in Salt Lake City APRIL 2024.

At least 20 Canadian patients, caregivers and advocates attended the CCF annual conference in Salt Lake City in April, which is a huge jump from attendance in previous years. CHCC was able to connect with numerous Canadian patients and caregivers, and we learned of several upcoming treatments in the United States that we will continue to follow with interest. It was also a chance for Canadians from B.C., Alberta, Manitoba, Ontario and Quebec to meet and share their experiences.



Many Canadians attended the CCF conference in Salt Lake City to share their experiences and learn of new breakthroughs

Progress on Pemigatinib (Pemazyre) Coverage.

In response to our advocacy, Alberta Health has approved coverage of pemigatinib for two patients with the FGFR2 fusion variant.



CHCC arranged interviews with CTV News on March 28, where Chris and Brenda shared their stories. Following the interview, CHCC had a meeting with Hon. Adriana LaGrange where we provided numerous information on cholangiocarcinoma and pemigatinib (Pemazyre). Minister LaGrange accepted the information CHCC provided and took some time to follow up with her own information-gathering, scheduling a follow-up meeting for May 3. While at the CCF conference in April, both patients mentioned in the interview Chris and Jennifer, received phone calls from Alberta Health regarding Minister LaGrange's decision to approve the drug coverage for them for one year.

'This has to change': New dad, grieving mom fighting for Alberta to cover rare cancer treatment
March 28, 2024.

Such good news for the cholangiocarcinoma community. This is the first second line targeted therapy to be covered by public funding for cholangiocarcinoma patients in the English-speaking provinces. (Quebec is covering Pemazyre under patient d'exception due to a positive recommendation, at this time). Hopefully this will open the door to approve more second line targeted therapies. CHCC continues to advocate across Canada for coverage for others with the same biomarker, and is pushing to have other patients' stories heard.

Ontario woman with incurable cancer pushing province to cover rare cancer drug | CTV News
May 28, 2024

<https://cfjctoday.com/2024/06/04/kamloops-woman-with-stage-4-bile-duct-cancer-pushing-for-coverage-of-expensive-treatment/> June 5, 2024

French Language on Website.

Cynthia Mitchell has graciously checked the French pamphlets on the website to ensure accurate translation. Thank you so much for your time and expertise, Cynthia!

Patient Story Corner.

Every newsletter, we ask for patient story submissions. Thank you for sharing your stories of hope and encouragement with other patients. You are not alone in this journey. If you would like to submit your story, please contact **newsletter@mychcc.ca**

BK's journey so far.

I was diagnosed with stage 4 Cholangiocarcinoma (Bile Duct Cancer) in November 2022. The diagnosis was a brutal shock as my husband, and I never thought this would be the outcome of my doctor's visits. I've been on three treatments since December 2022. I didn't have a significant response to Gemcitabine/Cisplatin/Durvalumab first line of treatment. I was enrolled into a palliative care program and started general chemotherapy called FolFox treatment in July 2023 which I had a better response to. I have been on a targeted therapy drug named Pemazyre since October 2023.

We asked for my liver tumour biopsy sample to be tested for any matches against clinical trials to try to prolong my life. My husband and I call this "My hail Mary"! We were lucky and a protein named FGFR2 in my cancer cells is targeted by a drug named Pemazyre. My quality of life with the



Pemazyre treatment is night and day compared to my chemo treatment. I have energy I didn't have while in chemotherapy to enjoy time with my family and friends and am taking a trip to Nova Scotia in June. I had so many appointments at the hospital and clinics when I was on chemotherapy treatments that I had a hard time doing anything else as appointments took up so much of my time and I didn't have the energy to do anything else after my appointments.

My husband has been my rock and my support for the last year and a half, and it would be harder to go through this without him. His company has been amazing with giving him time off when he needs it and have supported us in other ways. My Mom lives in the same city as me and supports my husband and I when we need anything. My family from my brother, aunts, uncles, cousins and my husband's family are there whenever I need to talk. They always seem to know when I'm having a low day and will send flowers, call, or text to tell me they are thinking of me. I don't know how I could have done all of this without my support network.

I am not sure what my next steps are as of right now, Pemazyre is not as effective as it has been, so we are looking into any other clinical trials or returning to the second line of chemotherapy. I am hoping there will be a new targeted therapy drug that will be as effective as Pemazyre has been for me.

I can't thank Brenda and the whole Cholangio-Hepatocellular Carcinoma Canada Charity enough. Without their help writing to my MLA and providing me with information and support, I don't think I would have had a meeting to ask for help getting Pemazyre covered in my province. My MLA presented my request to the BC Health Minister, and I am hopeful we make progress and spread the work about cholangiocarcinoma and Pemazyre.

MC's journey so far:

My name is MC. I am a wife and mother, an advocate and fundraiser, and a finder of hearts...

In October 2021, after an ultrasound to investigate unusual heartburn, I was diagnosed with cancer of an unknown primary. Several months and many tests and scans later, it was confirmed in December 2021 that I had CCA. I was fortunate enough to have a resection in January 2022, but unfortunately, I had a reoccurrence shortly after, and have been living with stage IV CCA ever since.

Thankfully, we were able to seek additional expert opinions both outside of Manitoba as well as outside of Canada, and my team at CancerCare Manitoba has a willingness to collaborate with others and are strong advocates for my care.

We learned early on that molecular testing was crucial to finding possible targeted therapies and clinical trials. Multiple tests at multiple labs provided us with insight into what my tumors might respond to and how they might behave. I learned of several targetable mutations with possible trials, including NTRK1, ERFF11, BRCA2, STK11, and MTAP Loss to name a few. After several months of chemotherapy and immunotherapy including Capecitabine, Gemcitabine, Cisplatin, and Durvalumab,



we moved to targeted therapies. I have had access to Larotrectinib, Entrectinib, and am now taking Erlotinib for my ERFF11 mutation.

From the time of my reoccurrence until October 2023 when I started taking Erlotinib, I had continued progression with multiple large masses taking over the right lobe of my liver. In the eight months that I have been on Erlotinib, my tumors have shrunk considerably, and, with any luck, the positive evolution of my disease will continue.

This targeted therapy has changed the course of my disease. At present my case is being reviewed for Histotripsy as well as a second resection!

This road has been long, unclear, and at times, nearly impossible to navigate. We are grateful for the love of friends and family along the way as well as the support of many organizations including the Cholangiocarcinoma Foundation, the Canadian Cholangiocarcinoma Collaborative, and Cholangio-Hepatocellular Carcinoma Canada (CHCC).

Since its inception CHCC has been instrumental in raising awareness, advocating for patients for a smooth road to diagnosis, as well as access to molecular testing, targeted therapies, and clinical trials. For me personally, the charity is providing me an opportunity to make connections, build community, and foster hope. Mentoring opportunities and engagement in advocacy initiatives are helping me to transform my own pain into meaningful purpose- something for which I will always be thankful.

Here's to research, community, and HOPE!

Upcoming Dates:

- **June 13 – Global Fatty Liver Day**
- **June 18** – CHCC Support group – Biomarkers talk with Dr. Faisal Khan from Oncohelix (Zoom). If you need the link, please email newsletter@mychcc.ca so we can send it to you.
- **June 20 & 21** – Free Biomarkers conference sponsored by CCRAN (Colorectal Cancer Resource Action Network) **Register For The Free Biomarkers Conference Now!** (click on link)
- **July 23** - CHCC support group
- **July 28 – World Hepatitis Day**
- **August 20** – CHCC support group



Education Corner

Liver cancer is the sixth most common cancer worldwide and the third leading cause of death, worldwide (National Cancer Institute, 2024). Despite the prevalence of this cancer, patients are often stigmatized due to misinformation about the strength of the relationship between alcohol consumption and liver cancer. To raise awareness of this widespread disease and its multiple risk factors, we are urging facilities and municipalities to **Light Up Green** across Canada for Global Fatty Liver Day and World Hepatitis Day.

Reference: National Cancer Institute (2024). Retrieved from <https://www.cancer.gov/types/liver/what-is-liver-cancer/causes-risk-factors>

Fatty Liver Disease

Fatty Liver disease, also called MASLD (metabolic dysfunction associated steatotic liver disease) is a risk factor for liver cancer. It affects approximately 20% of all Canadians and occurs when too much fat is stored in the liver. “Fatty liver disease typically develops when a person consumes more fat and sugars than their body can handle: more common in overweight and obese individuals but can occur in people with healthy body weights” (Canadian Liver Foundation, 2023).

Reference: Canadian Liver Foundation (2024). Retrieved from <https://www.liver.ca/?s=fatty+liver+disease>

Hepatitis

Hepatitis (especially Hepatitis B and C) are the most common causes of cirrhosis of the liver, liver cancer and other viral hepatitis-related deaths. According to the World Health Organization (WHO), 354 million people globally live with Hepatitis B or C. While vaccination programs are available for Hepatitis A and B, there is currently no vaccination for Hepatitis C.

Reference: World Health Organization (2023). Retrieved for www.who.int

To volunteer with CHCC, please go to the “Contact Us” tab at www.mychcc.ca and send us a message. We would love to hear from you.