



## Cholangio-Hepatocellular Carcinoma Canada Newsletter

Volume 1, September 2024

### **Welcome!**

Welcome to the second issue of the Cholangio-Hepatocellular Carcinoma Canada (CHCC) newsletter.

### **Slogan**

CHCC would like a catchy slogan that is meaningful to patients and caregivers.

Here are some suggestions given to us:

- Growing Hope Together
- Growing Possibilities Together
- Together: Hope + Possibilities = Action
- Hope + Advocacy = Possibilities
- Growing Advocacy together

Please register your selections in this straw poll: <https://strawpoll.com/xVg71Q1K6yr>

If you do not like any of these, please email another suggestion to [newsletter@mychcc.ca](mailto:newsletter@mychcc.ca)

### **Biomarkers**

**June 20, 2024** – Biomarkers are uppermost in everyone's minds and how they affect the treatment of cholangiocarcinoma.

Dr. Faisal M. Khan was kind enough to hold a Zoom meeting with CHCC to discuss biomarkers and their connection to cholangiocarcinoma. A meeting video is available on the website and our [YouTube channel](#). Dr. Faisal M. Khan is a professor at the [University of Calgary](#) and co-founder and CEO of [OncoHelix Inc.](#) This organization specializes in providing esoteric cancer genomic and immunology testing.

### **Progress on Pemigatinib (Pemazyre) Coverage.**

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

**June 13, 2024** - [CTV News] [Alberta's coverage of new treatment for rare cancer provides hope for patients](#). A new dad from the Calgary area is feeling hopeful after the Government of Alberta agreed to cover the cost of a new cancer treatment that might improve his chances of seeing his daughter grow up.

**July 23, 2024** – [CTV News] <https://kitchener.ctvnews.ca/kitchener-woman-hopes-ont-follows-other-provinces-in-covering-rare-cancer-drug-1.6974713> A young mother in Ontario needs coverage for pemigatinib.

CHCC is continuing to advocate for Pemazyre coverage for all patients across Canada. We have teamed up with eight (8) other organizations (including C3, CCRAN, CCF, SYSF, CCSN, CGOEN, CORD, and CanCertainty) and wrote a letter to the Ontario Health Minister, advocating for



pemigatinib (Pemazyre) coverage for patients with the FGFR2 fusion biomarker. We will also continue to write to other provincial Health Ministers.

### **New drug, Tibsovo (ivosidenib), approved for cholangiocarcinoma**

In July, Health Canada approved a new drug for Canadians. Ivosidenib is the drug used in targeted therapy for the IDH1 biomarker. This biomarker occurs in both intrahepatic and extrahepatic CCA. Unfortunately, Servier (the supplier) has been unable to obtain a supply of drugs for Canada yet. They hope to have the drug available by mid-October. At this point, it is unknown if they will have a Patient Support Program for patients who do not have insurance coverage. They have not submitted the drug for reimbursement to CDA (CADTH) or INESSS yet. When CHCC finds out the information, an email will be sent to everyone.

### **Another first line therapy approved for cholangiocarcinoma**

Pembrolizumab (Keytruda), a checkpoint immune inhibitor, has been approved for first-line therapy in combination with gem/cis (chemotherapy) with locally advanced metastatic or unresectable biliary tract carcinoma (BTC). (This is an alternative to gem/cis/durva.) Patients can either have gem-cis-durva or gem-cis-pembro. This can only be ordered by physicians with expertise in treating BTC.

### **Patient Story Corner.**

In 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. These stories are in the words of the patients and/or caregivers. If you would like to submit your story, please get in touch with [newsletter@mychcc.ca](mailto:newsletter@mychcc.ca)

### **SA's journey to date**

*My brother SA was diagnosed with Stage 4 Cholangiocarcinoma with mets to liver and nearby lymph nodes in October of 2023. His symptoms were swollen feet and shortness of breath. Most people with this cancer are jaundice and get diagnosed as stage 4.*

*During our first visit to see our oncologist, we were told to get his affairs in order as he was inoperable and incurable. We asked about clinical trials but were told that they are expensive, you would have to uproot your family, move to another country or go without seeing family, who knows how long it would entail and that it was more important to lead a quality life for as long as he had left.*

*We were completely devastated by this news. My brother was diagnosed at age 58 and has a wife, son (16) and 2 daughters (19 & 24 ) that he hopes to see get married and have grandchildren one day. He runs the HH and is the rock in not only his own family but our entire family and is loved by all.*

*We are keeping my brother's name disclosed and anonymous (as per my brother's wishes) because he decided he didn't want to share his diagnosis with everyone and more importantly decided to keep it from his elderly mother as this could potentially kill her from worry as she has a heart condition.*



*After crying ourselves to sleep every night for over a month facing the fact that my brother may not live, we decided we were going to fight this disease and do whatever it takes to get him cured / NED (no evidence of disease).*

*I researched like crazy, found inspirational stories of people all over the world with the same cancer and sought out to talk to everyone we could and gather whatever info we could that would benefit my brother.*

*Thankfully, my niece found the FB group for Cholangiocarcinoma that we joined and that was the start of the most amazing support system and information, not to mention friends made from this group/ CCA Foundation. It's like having a 2<sup>nd</sup> family as everyone is so caring and sharing is caring as they say. I honestly don't know what I would do without either of these groups. One of the first things I found out was that we must do genomic testing to see if we have any targetable mutations. We brought it up with our oncologist and were told it could take up to 6 months so we decided to pay for it on our own \$2200 through Foundation One and got the results back within 2 weeks. We found out that he is dMMR (deficient mismatch repair) and MSI-H, TMB-H which is like hitting the jackpot with this cancer as some would say and gave us hope. We also reached out to the Canadian CCA charity and American CCA Foundation who have been amazing, kind and extremely helpful as we navigate through this journey.*

*My brother's first-line treatment was cis/gem/durva which is considered the gold standard (first-line treatment) for cholangio. He lost approx. 35 lbs in the first 6-8 weeks and slept a lot but then started to gain weight again and has been living a pretty normal life with zero issues thankfully. After 3 months we received his first set of results in March which showed 47 – 82% shrinkage!! We were ecstatic and even more hopeful. We stayed the course and everything was pretty stable next scan in June. No further shrinkage. Since we had such big shrinkage in the first scan we expected to see additional shrinkage so it was disappointing to see there was no improvement, however stable with this cancer is considered good so we have stayed the course.*

*In the meantime, we decided to get a 2<sup>nd</sup> opinion and went to MD Anderson in Houston Texas at the end of March and saw Dr. Hu who works closely with Dr. Javle (top CCA specialists). He advised us to get off the gem/cis/durva and just do 100% durva moving forward. We ended up doing 10 cycles of gem/cis/durva before we started on 100% durva. We just received the results and the durva is working as a monotherapy. We saw approximately 20% shrinkage in the largest tumour. **Hip Hip Hooray!** The doctor recommended holding off doing radiation or histotripsy as we are still getting promising results on durva alone and we hope that we get more shrinkage along the way.*

*Through the help of the Canadian CCA charity, we got the names of 2 cholangio specialists and wrote letters to them. However, were told that we couldn't pick and choose our oncologist and were assigned an oncologist regardless of specialty. Our oncologist is lovely, but we felt the need to advocate for someone who specializes in CCA and knows how to fight this cancer. It would be great to speak to someone who actually knows the latest treatments and understands this rare disease.*

*What we are realizing is that the oncology dept in BC is overwhelmed to no fault of theirs. Unfortunately, that's not good enough for us if we want a chance for a cure. We have realized*



*that any patient with mets will only get the basic 1st line treatment, nothing more as it's too costly for our health care system. Thankfully, we have the financial means to get treatment in the US which has several options. The doctor here in BC said if immunotherapy stops working we can go back to chemo but they will stop covering immunotherapy. Any other immunotherapy will be a cost to my brother and the cost is huge. We are currently reviewing our options and considering histotripsy, Y-90, radiation, more chemo, clinical trials and other immunotherapy options as our 2<sup>nd</sup> line treatment as suggested by our USA doctor if durva stops working. Dr Hu seems to have lots of options in his war chest.*

*The moral of our story/journey is that you need someone to advocate for yourself and explore every option out there. The Canadian system is strapped and broken in our opinion or at least in BC it is. Find an oncologist that will support you and advocate for you. The USA is further ahead in many treatments that are not available in Canada yet. Look for histotripsy to be here in 5 years maybe.....but don't give up! Speak to as many people as possible. Attend seminars, webinars, etc. Organize a binder with all your labs, scans, oncology notes, and documentation. Ask for a CD / copy of all your imaging when you get it done, for your files in case you need to send it to anyone for a 2<sup>nd</sup> opinion. Information is key to fighting this disease.*

*We still have a lot of work to do and the fight continues..... Everyone with this disease pretty much is stage 4 when diagnosed. I've seen and read so many people living 5, 10, 15 years with this disease and many that are NED. Stay strong, never give up and NEVER lose HOPE!! Best wishes to all fighting this disease and their caretakers. Our prayers are with you all.*

*SA's brother (anonymous)*

**JN's journey to date:**

*Do you ever wake up and wonder how did I get here?*

*Well, I still have days where this happens, even after being diagnosed with Cholangiocarcinoma in January 2023 and over a year of chemotherapy treatment, surgery, tests and a few too many ups and downs with my health.*

*I had spent 2022, exhausted mentally and physically. I could not figure out why even after a weekend spent at home recharging and catching up on sleep, I would start the week even more tired than the week before. I was out of breath walking my dogs in the hills around our home and thought I guess this is what early fifties is like. After a routine blood test with my family doctor in January 2023, I had one elevated liver enzyme, which was odd for me. Just in caution, my family doctor ordered an ultrasound of my liver. I had a right-sided liver tumour just over 10 cm's in size with numerous other smaller tumours. A biopsy in February confirmed CCA.*

*I too could have never imagined this was my outcome. I struggled with trying to understand how I developed such a specific, aggressive, rare cancer. No family history, and no risk factors.*



*But I realized early that I did not have the time to try and figure out how this had happened, I needed to jump into getting treatment, understanding my options, and pushing for a sooner appointment with my new oncologist.*

*One thing that really resonated with me was what a good friend told me, believe in possibilities, not probabilities. I have carried these words with me each step through this journey. Unfortunately, my tumour was not resectable. Surgery was not an option as the tumour was too large, so I started chemotherapy (Cisplatin, Durvalumab, Gemcitabine) as my treatment plan in March 2023 to shrink the tumour and see if surgery would be possible.*

*I did well on chemotherapy, physically I could manage the predictability of the sick days that follow chemo and felt like I was finally taking action in a situation that was so much not in my control. I was fortunate to respond well to my chemotherapy and my tumour did not really shrink a lot, but no new tumours developed, and I had a liver resection in August 2023.*

*Surgery was successful until December 2023, my cancer was back and aggressively. I now have tumours in my liver, abdomen and lungs. I had the original main liver tumour tested for biomarkers and confirmed I have the FGFR2 gene, which can be treated with the targeted therapy drug Pemigatinib (Pemazyre).*

*I started chemotherapy again in January 2024 until just this mid-September. Unfortunately, my body, bone marrow and kidneys can no longer take the chemo and its time to change my treatment plan. I will be starting the targeted gene therapy drug Pemigatinib this week. It's hard to accept this change or progress in this disease, but equally, I am so grateful for Brenda and the entire Cholangio-Hepatocellular Carcinoma Canada charity. Brenda was a powerhouse in advocating on my behalf with the provincial health minister to ensure my targeted drug was covered. I know I would not have had the skills to navigate the government nor the energy to do it. Brenda and the charity have provided me with invaluable knowledge, and support and given me hope to stay positive, keep asking questions and seeking options.*

*This last year and a half have had so many ups and downs and I can honestly say it's the kindness of friends and family that gives me the strength to stay in the light. From friends checking in each and every night, to coolers full of pre-made meals or many deliveries of comfort food and kindness. I feel blessed and so grateful. My husband KN has been my rock and has helped me recognize and appreciate the beauty and the little victories, even on the bleakest days.*

*Receiving my chemo treatment from the rural hospital in High River, has been a huge benefit for my spirit and mental health. The personalized care provided by the nurses and doctors has been so supportive and kind. I look forward to heading to the cancer care clinic for treatment, because they are so genuine and encouraging.*

*I believe this is just one chapter in my life and there is a lot more to be written. This diagnosis has given me a whole new perspective on community, the beauty of everyday events and the power of detours and the spirit to believe in possibilities and recovery with the help of science, research and hope.*





### **Upcoming Dates:**

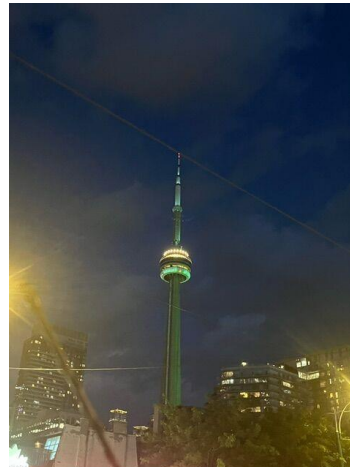
- **September 17** – CHCC support group
- **October 15** – CHCC support group
- **Nov 14 & 15** – Free “Early Age Onset Cancer Symposium” sponsored by CCRAN (Colorectal Cancer Resource Action Network.) Click on this link to register for the conference. [Webcast - Lobby \(meetview.com\)](#) ]  
An article related to this symposium [The Alarming Rise in Early Age Onset Cancer: CCRAN's Call to Action — Health Insight](#)
- **Nov 19** - CHCC support group
- **Dec 17** – 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. Fatty liver disease and hepatitis are the two biggest risk factors for hepatocellular carcinoma. On June 13 and July 28, places across Canada lit up **green** to show support for fatty liver disease (June 13) and hepatitis (July 28). Check out the website for places across Canada that did light up **green**!



**Winnipeg**



**Toronto**



**Calgary**



**B.C. Legislative Grounds, Victoria**

To volunteer with CHCC, please go to the “Contact Us” tab at [www.mychcc.ca](http://www.mychcc.ca) and message us. We would love to hear from you.