Cholangio-Hepatocellular Carcinoma Canada (CHCC) Volume 2, No. 1 March 2025

Welcome!

Welcome to the first issue, volume 2 of the 2025 Cholangio-Hepatocellular Carcinoma Canada (CHCC) newsletter.

February 20, 2025 World Cholangiocarcinoma Awareness Day "Light Up Green"

Facilities across Canada lit up green to bring awareness to this rare and aggressive cancer. Just click on the link to view the YouTube video of all the places that lit up green!
https://www.youtube.com/watch?v=GCcxycqefIc

Slogan

In the last issue, CHCC asked for input into a catchy slogan. The slogan that won was "Inspiring hope together," which reflects our collective mission to support each other and foster a sense of hope in the face of cholangiocarcinoma and hepatocellular carcinoma.

Progress on Pemigatinib (Pemazyre) Coverage.

As soon as we hear the results from the CDA regarding their recommendations for reimbursement, we will email everyone. We expect to hear by April 3, 2025.

Clinical trials that are happening across the country

IDH-1 biomarker: Tibsovo (ivosidenib) Servier

There are clinical trials that are still recruiting in Calgary, Toronto (Princess Margaret Cancer Centre and Sunnybrook) and across Canada for cholangiocarcinoma (CCA) patients who have the IDH1 biomarker.

HER2 expressing tumours: Trastuzumab deruxtecan (T-DXd) AstraZeneca

Click on the hyperlink to clinicaltrials.gov details for DPT-02 with listing of sites across Canada and US.

Phase 1 clinical trial for the Safety of BAY 3547926 Bayer

This trial is for patients with advanced liver cancer and recruiting happening in Quebec, Ontario and Alberta ClinicalTrials.gov ID NCT06764316 (click on hyperlink)

Patient care kits

Thanks to AstraZeneca, Incyte and a local Red Deer dentist's office, we are able to provide patient care kits for new patients diagnosed with either cholangiocarcinoma or hepatocellular carcinoma. Your well-being is our priority, and we're pleased to share that we've already sent out over 17 care kits! If you know anyone newly diagnosed or without a patient kit, please contact **newsletter@mychcc.ca**.

Mentorship program

A CHCC mentorship program start-up committee for patients and caregivers has been meeting since January 2025. This program aims to provide a supportive network for those affected by cholangiocarcinoma and hepatocellular carcinoma, offering guidance, shared experiences, and emotional support. Neil Marr is the committee chair, and Mohammed Islam, Julie Davlut, and Brenda

Clayton are committee members. More details will follow. For more information, please visit our volunteer page on www.mychcc.ca . We will start this program in April 2025.

Meet-ups across the country

Winnipeg - Meet up on Sunday, March 23, 10:30AM at Stella's Bakery on Corydon
Calgary – Meet up on Thursday, March 27, 10:00AM at the café just outside Heritage Park.
Everyone is welcome to attend either meet-up.

If anyone else has any planned meet-ups locally, please let us know so we can mention it in the newsletter.

Canadian Cholangiocarcinoma Collaborative

C3 is hosting a 'Meet the C3' conference on April 4-6, 2025. For more information, contact Leonard at **langka@ohri.ca**.

People ask what the difference is between C3 and CHCC. We are two different organizations.

The **C3** is a clinical organization based out of the Ottawa Hospital Research Institute. The C3 was founded in 2023 and is funded through a 5 year Canadian Cancer Society and Canadian Institutes of Health Research Breakthrough Team Grant. The C3 was formed to grow hope among the patients and families, oncologists and researchers with whom they have formed a partnership. The C3 provides patient support, access to molecular testing, expert opinions and opportunities to participate in on-going research programs.

CHCC is a community based registered Canadian charity which advocates for individuals with cholangiocarcinoma (CCA) and hepatocellular carcinoma (HCC) by providing assistance to information, group support programs, and advances education by providing webinars and educational materials to those individuals with CCA and HCC, and to their families and caregivers. CHCC is funded through donations from individuals and organizations.

Both organizations benefit the patients!

CCRAN's article from conference on Biomarkers 2024

This article is a result of the Biomarker conference that CCRAN hosted last year. It contains a lot of valuable information as it speaks to the issues of biomarker testing (comprehensive genomic testing) across Canada from a patient, caregiver, and physician point of view. The link is here to access the article, "Toward Timely and Equitable Advanced Biomarker Testing for Patients with Metastatic Cancer in Canada."

CCF Annual Conference

This event is happening on April 9-11. Canadian patients interested in attending the annual Cholangiocarcinoma Foundation conference were able to apply for a scholarship. We look forward to connecting with everyone in Salt Lake City.

Patient Story Corner.

In every newsletter, we invite you to share your patient stories. Thank you for sharing as your experiences of hope and encouragement can make a difference in the lives of other patients. You are not alone in this journey. If you'd like to share your story, please get in touch with **newsletter@mychcc.ca**.

T and H's story

CONNECTING THE DOTS

Our Story is a testament to family; friendships; research & educational information; love; prayer & relentless ADVOCACY! Trying to manage a loved one with a terrible; rare cancer; in a system you are not familiar with; is extremely scary and overwhelming. The Really Positive and Wonderful news is that there is plenty of fantastic work happening!!! All one has to do is; CONNECT THE DOTS!!!!

This journey that started in Florida on January 29, 2023 from an Emergency room visit; on a Sunday morning; that turned out to be a UTI; but with a CT scan initiated as a matter of routine; at this facility a 9.5 cm tumour was discovered in T's liver.

We came home with the CT scan; blood test results and an MRI that was completed in Florida. I forwarded all this information to our family doctor. We arrived back home on February 20th, 2023. Our family doctor had made arrangements for a Blood test that same day to test for blood cancer markers. This test result came back later that week indicating high CA 19-9 that is an indicator of Cholangiocarcinoma. He contacted our surgeon who looked at the MRI that was brought back with us from Florida and immediately said this was Intrahepatic Cholangiocarcinoma; a biopsy was ordered that later confirmed his initial thoughts.

Chemo with an immunotherapy drug was started to get this tumour small enough for liver resection. Chemo started in April 2023 and 16 treatments later; ended in October 2023 with CT scan that showed the tumour shrinking in 1/2. This CT scan also showed a 9mm growth on T's L3 vertebra that was suspected to be a cancerous lesion. We had it radiated as a precaution. This lesion has been scanned every three months up to December 2024 and showed no sign of change and no other abnormal growths noted. However, this was classified as T's cancer had metastasized; taking liver resection surgery off the table.

T continued on in November 2023 with immunotherapy drug only; once a month for the coming year. T was scanned in January 2024 and the tumour in her liver showed no sign of increase in size so Immunotherapy was continued. In April 2024 another CT was completed showing the tumour had grown 2.5 cm. Immunotherapy stopped and immediately back on Chemotherapy. Another 18 Chemo *treatments completed on October 17, 2024. Again, CT scan showing liver Tumour shrinking down to 1/2 the original size and the L3 vertebra lesion showing no difference in over a year since it was first seen.*

This journey has been a nightmare; a whirlwind!!!!!; and in many cases & at many times A BLESSING!! We have met wonderful people & we have even closer relationships with our friends that pray for us everyday and we / I am learning more and more about the POSITIVE work going on in research and advocacy for Cholangiocarcinoma.

Through friends from Ottawa in late April 2024 we were connected to an organization working out of the Ottawa Research Hospital called ***“Canadian Cholangiocarcinoma Collaborative (C3)”.*** *Their mission is to* ***translate hope into better outcomes*** *by enhancing patient access to personalized testing, expert opinions and treatments, including targeted agents and immunotherapy through clinical trials, and to create a high-quality immunotherapy pipeline for novel therapeutic discoveries.*

We met the Organizations Navigator Christine LaFontaine; who put us on to Dr. Rebecca Auer (oncology surgeon) and current CEO of The Ottawa Research Hospital. Dr. Rebecca has a family member that has Cholangiocarcinoma. She is a co-founder of the noted organization.

End of June 2024 we met Dr. Rebecca on Zoom. She reviewed our case with us and wanted to take T’s case to her tumour board in the Fall when they reconvened. We Agreed. She also instructed Navigator Christine to get a full Molecular Test run on T’s biopsy to look for any additional cancer mutations that may be within the tumour. The organization paid for this molecular Report and it did identify two additional cancer mutations unknown previously: IDH1 and KRAS. This was sent to T’s local oncologist in St. John’s.

Through the Summer and Fall of 2024 I attended monthly patient advocate meetings and this is where I met Brenda Clayton; one of the founders of another charitable organization out of Red Deer AB. Cholangio-Hepatocellular Carcinoma Canada.

Below picture is T this past August 2024 in Corner Brook, NL when we were on our 10-day break from Cisplatin and Gemcitabine Round 14; after 28 Chemo Treatments since April 2023. 3 more rounds; 6 more Chemo treatments completed on October 17th, 2024.

We managed to catch two of our grandsons playing back-to-back weekend tournaments; one in All NL soccer tournament; the other in all NL baseball tournament. Amazingly both grandson’s teams won their championships. T will win her Championship as well!!🙏🏻🙏🏻🙏🏻🙏🏻

In early October Dr Rebecca Auer presented T’s case to her National Cholangiocarcinoma Tumour Board and we received a report from that review. This was also sent to our Oncologist in Eastern Health.

We completed the 18 Chemo sessions (9 rounds) on October 17, 2024. We spent 5 weeks in Florida building mental & physical strength back.

As a result of the Ottawa Tumour Rounds being shared with our Health science oncologist, and based on the reports recommendations, we had a PET scan (that got initiated with help from friends and the Ottawa C3 research group Dr. Rebecca Auer & Christine LaFontaine). On December 11, PET scan results showing no metastasis; this put T back on the surgery list. MRI for surgery consideration was done on January 9, 2025. Communication from Surgeon on January 10, 2025 indicating surgery booked in St Johns for January 30, 2025. Pre surgery consultation meeting with surgeons on January 20.

It's hard to believe that on January 30, 2025; two years to the day since this all started for us; T had a 7-hour surgery that went off textbook carried out by our two local liver surgeons. After surgery our surgeon came out to inform me that the resection is R0——This indicates that all visible tumour tissue has been completely removed with negative margins. 🙏🏼🙏🏼🙏🏼

T is now home as of February 5 recovering from the surgery that took 60% of her liver. She is doing well!!

We will also attend the Canadian Cholangiocarcinoma Collaborative (C3) conference in Toronto on April 4-6, 2025.

We will go to the Salt Lake City Cholangiocarcinoma US conference; and with all the STARS ⭐⭐⭐⭐ *aligning April 8-11.*

The Green lights are approved to be turned on St. John's City Hall and The Confederation Building for the "WORLD CHOLANGIOCARCINOMA AWARENESS DAY "on February 20th!!!

Updates from patients from previous newsletters:

Update from SA's brother (anonymous)

S had the histotripsy procedure on Friday Jan 10, 2025 in Oroville, California with Dr. Burns. Dr. Ercolani from Oroville gave us the date of Jan 10, so we immediately accepted and took that date as a sign to move forward, as it was our late dad's birthday. 😊 *We arrived on Wed Jan 8th and flew home on the 11th. Thank you to Dr. Ercolani and his team for organizing this. The entire process from start to finish was seamless. We are from Vancouver, BC Canada and self paid and we were so impressed how smooth the entire process went. The cost was $50K US / $75K Canadian* 😟*, which includes your hotel and all your transfers. All you need to do is organize/pay for your flight and for your food. It was easiest for us to fly into Sacramento (2 hr flight) instead of San Francisco as its only a 1.5 hr drive to Oroville. San Francisco is a 3.5 hr drive to Oroville. From the limo pickup from the airport, to the hotel, to the shuttle taking us to and from the hotel/hospital, the check in, triage, staff, nurses, etc, everyone was so kind and wonderful. It's an older hospital in a very small town with* *nothing to do there really but that wasn't an issue at all as they have the histotripsy machine and that's why we went there. Dr. Burns goes to Oroville once a month to perform Histotripsy in Oroville and works out of Mission Viejo the rest of the time doing Histotripsy there, so Mission Viejo is another option to get this done at.*

S's tumors in his previous MRI's/scans always showed that my brother had very large tumors, 8.5 cm, 7 cm etc and we were initially expecting to do a partial procedure as we've never really ever been told how many tumors he had as it was always noted as a very large mass. His initial diagnosis was stage 4 cholangio with Mets to liver, right adrenal and nearby lymph nodes. For this procedure the tumors typically need to be 5cm or less to eradicate them and for bigger tumors they can only do partial.

Dr. Burns advised us that he was able to target 4 X 4 cm tumors that were clumped together and he advised us that he got them all. I guess since they were clumped together, it was hard to tell exactly the number of tumours my brother actually had, so we were ecstatic that Dr. Burns got them all. The entire procedure was 220 minutes and when my brother woke up, he had very mild pain. They did a CT scan after the procedure and then we were free to go. There was no waiting for anything. My brother's pain was a 1 out of 10. The entire process was so smooth. The next day Dr. Burns called to check on him again and he had a slight fever (as to be expected, and were told he would experience) and we flew home that day (on Saturday). Honestly the entire trip was seamless and I would highly recommend it. Huge thanks to Dr. Ercolani and his team at Oroville Hospital and Dr. Burns for his amazing work with the Histotripsy procedure. This procedure has the ability to save so many lives with CCA or extend their lives until they find a cure or until the next newest technology becomes available. Honestly this was a no brainer for us and with nothing to lose. We are ecstatic with the outcome thus far and on Feb 26th my brother will have his MRI and results thereafter, that we will share as soon as we get them.

Only 20% of patients apparently have the abscopal effect and Dr. Burns said of those that have had the abscopal effect he has seen it mostly in Cholangio patients. The abscopal effect is when your immune system kicks in and recognizes the cancer and goes after it and kills it.

One of my American friends whose father had an 8.5 cm tumor went to see Dr. Burns for a partial histotripsy procedure to relieve some of the pressure on the liver and the 1 month MRI after the procedure showed his tumor completely gone.

One thing to make note of that we've been told from another oncologist in the US, because this is a fairly new procedure it could trigger something else in the body in the form of another tumor or something else. No one knows for sure and unsure if it's just a coincidence, or it's just progression or if indeed the histo caused this. That would be my precautionary measure however since we have limited options for treatment in Canada and time is of essence. Our rationale was to go for it and take some pressure off the liver long enough until the next new procedure or cure comes into play.

My brother and I wish everyone the very best on their Cholangio journey and pray for a cure for everyone soon.
Our very best wishes to all

SA's brother (anonymous)

Board Updates

There will be an annual general meeting on May 31, 2025.
We have two openings for Board members. If you are interested, the criteria are as follows: you must be Canadian, over 18 years old, and volunteer with the organization.
Anyone can attend the meeting, but to vote, you must make a $25 donation through CanadaHelps.
All interested individuals must complete and send their applications to CHCC by May 15. Elections will occur after that, and the President will announce the successful new Board members at the May 31 meeting.

Upcoming Webinars

Several webinars are in the planning stages. When the dates are confirmed, information will be sent to everyone.

Upcoming Dates:

- **March 4 –** CHCC Bereavement support
- **March 18** – CHCC support group
- **April 1 –** CHCC Bereavement support group
- **April 4 - 6** – Meet C3 in Toronto
- **April 9-11, 2025** – CCF conference in Salt Lake City
- **April 15** – CHCC support group
- **April 19 – World Liver Day**
  Light up green
- **May 6, 2025** – Bereavement support group
- **May 20** – Patient support group
- **May 31 - ANNUAL GENERAL MEETING at 1000 MDT. Pre-register please.**
- **June 3 –** Bereavement support group
- **June 12 – Global Fatty Liver Day**
  Light up green
- **June 17 –** Patient support group

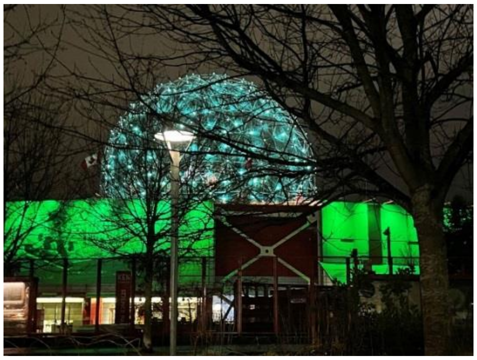
Education Corner

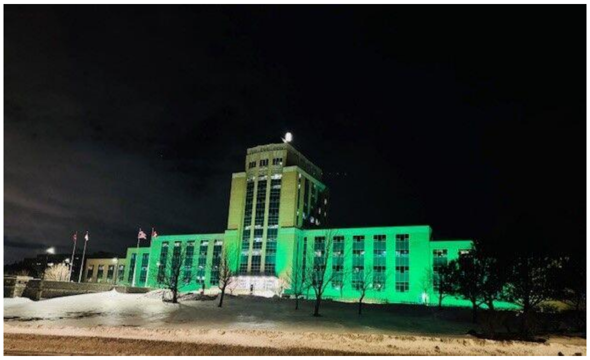
At one of our meetings, one of our members asked how a rare cancer is defined. There seem to be so many cases. In Canada, the Canadian Cancer Society (2023) defines a rare cancer as one in which less than 6 people are diagnosed with it for every 100,000.

The TARE and Y-90 treatment question came up in one of our discussions. In March 2021, CADTH approved TARE with Y-90 for intermediate or advanced stage hepatocellular carcinoma, including patients with recurrent or advanced HCC. TARE and Y-90 can occur at any major centre. It is performed by an interventional radiologist. As mentioned, it is usually used to treat HCC patients, and if any patient with CCA wanted to try this, their case would have to be presented at tumour rounds.

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 April 19, June 12 and July 28, places across Canada will again be asked to light up green to show support for fatty liver disease (June 12) and hepatitis (July 28).

This is an excerpt from Canada's Guidance on Alcohol and Health: Final Report: "It may be unsettling to learn that alcohol is a carcinogen related to at least 7 cancers, including common ones like colon and breast cancer and it is a main cause of liver diseases, which are on the rise in Canada. Current evidence shows that drinking a little alcohol neither decreases nor increases the risk of ischemic heart disease. In fact, alcohol consumption is a risk factor for most types of cardiovascular and lower respiratory infections as well as injuries resulting from violence. It is clear that people should not start to use alcohol or increase their alcohol use for health benefits. Hence, this project has confirmed that when it comes to drinking alcohol, less consumption means less risk of harm from alcohol and from this fact, it is necessary to promote the message that it is okay not to drink alcohol." (Canadian Centre on Substance Abuse and Addiction (2023). Canada's guidance on alcohol and health:Final report. Retrieved from: www.ccsa.ca)


Science world (Vancouver)


Confederation Building (St. John's, NL)

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