

#### Welcome!

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

#### June 12 Global Fatty Liver Disease Day, 2025 "Light Up Green"

Facilities across Canada lit up green to raise awareness for 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 25% of all Canadians and is when too much fat is stored in the liver. This is non-alcoholic in nature (Liver Canada, 2025)

Click on the link to view a gallery of all the places that lit up green!

# **July 28 World Hepatitis Day 2025**

Facilities across Canada lit up for awareness of Hepatitis. Chronic infection with hepatitis B and C viruses is the most significant risk factor for liver cancer worldwide. Click on the <u>link</u> for the slideshow of some places that lit up for World Hepatitis Day.

#### **Exciting news for Ontario residents.**

Let's hope this spreads to the other provinces as well. Click on the link: "Ontario government aims to fast-track cancer drugs in new pilot project."

#### Clinical trials that are happening across the country

# All-comer trials in HCC or BTC: ARTEMIDE-HCC01 AstraZeneca

Click link here for details.

#### **ARTEMIDE-Biliary01 AstraZeneca**

Click link here for details.

# **Biomarker specific Clinical Trials**

# IDH-1 biomarker: Tibsovo (ivosidenib) Servier

Clinical trials for cholangiocarcinoma (CCA) patients with the IDH1 biomarker are still recruiting in Calgary (Arthur E. Child), Toronto (PMH and Sunnybrook).

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

Click on the hyperlink to clinicaltrials.gov details for <a href="DPT-02">DPT-02</a> with listing of sites across Canada and US. NCT04482309

# **Destiny BTC01 AstraZeneca** T-DXd and Rilvegostomig Versus SoC in **Advanced HER2-expressing Biliary Tract Cancer**

Click on the <u>link</u> here for more details.

NCT06467357



**CLARITY-PanTumor01 AstraZeneca** for tumours expressing **Claudin 18.2** biomarker Click on <u>link</u> here for more details.

# 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)

#### Phase 1/2 clinical trial for Cogent Trial Drug CGT4859 Cogent Biosciences Inc.

This is a FGFR2/3 inhibitor drug. For more information contact Diane Arndt RN, BScN, Lead Nurse at (phone) 780-989-8157; (fax) 780-577-8138 or email at <a href="mailto:diane.arndt2@albertahealthservices.ca">diane.arndt2@albertahealthservices.ca</a>

<u>Tinengotinib access.</u> The success of Tinengotinib is on this <u>link.</u> If you wish to participate in the clinical trial in USA, please contact Priya Priyadarshini at <u>priya.priyadarshini@syneoshealth.com</u>.

<u>When combined with TACE, imfinzi and bevacizumab</u> offer a clinically meaningful improvement in PFS for patients with intermediate-stage HCC, potentially setting a new standard of care in this area.

<u>Clinical Trials Map</u> that you can access yourselves, thanks to Matt Reidy at Genomic Focus. Click on the link <u>www.clinicaltrialsmap.org</u>

#### Patient care kits

Thanks to AstraZeneca, Incyte, Merck and Strembiski Dental, a local Red Deer dentist's office, we can provide patient care kits for new patients diagnosed with either cholangiocarcinoma or hepatocellular carcinoma. Your well-being is our priority. If you know anyone who is newly diagnosed or without a patient kit, please contact info@mychcc.ca.

#### Mentorship program

A CHCC mentorship program started in April 2025. This program aims to provide a supportive network for those affected by cholangiocarcinoma and hepatocellular carcinoma, offering guidance, shared experiences, and emotional support. To access a mentor (as a mentee) or to volunteer as a mentor, please visit our volunteer page on <a href="https://www.mychcc.ca">www.mychcc.ca</a>. We look forward to working with both mentors and mentees.

#### Meet-ups across the country

(Please let us know of any other local meet-ups so we can include them so everyone has a chance to join.)

**Winnipeg** - Meet up on third Sunday of every month at 10:30 AM at Stella's Bakery on Corydon. Contact <a href="mailtobacca@gmail.com">manitobacca@gmail.com</a> for more information.

**Calgary** – Meet up on the last Wednesday of every month at 10:30 AM at the Railway café outside Heritage Park. Everyone is welcome to attend either meet-up. If anyone requires more information, go to <a href="Cholangio-Hepatocellular Carcinoma Canada">Cholangio-Hepatocellular Carcinoma Canada</a>.



# Register for the Canadian support groups by:

To register, go to <a href="https://www.mychcc.ca/index.php?page=calendar&lang=en">https://www.mychcc.ca/index.php?page=calendar&lang=en</a> Thanks in advance for reaching out.

# Save Your Skin conference November 2025

Register for Save your skin conference in November.

It is free. If you miss any sessions, they will be available afterwards to those who signed up.

The link is <u>Patients Redefining the Future of Healthcare in Canada Summit Tickets, Tue, 25 Nov 2025 at 8:00</u> AM | Eventbrite

#### **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 contact <a href="mailto:info@mychcc.ca">info@mychcc.ca</a>.

# This is MRs story as told by his daughter.

My father, MR, was diagnosed with hilar CCA in July 2024. The signs were there for a while and yet we hadn't known. The immediate signs showed up soon after, my father's eyes had turned yellow and the next thing we knew, he was in the hospital with elevated liver enzymes, a CT scan showing it was likely cancer. A failed ERCP, a bleed out, 2 infections and 2 biliary tube insertions later, my father had survived the first three weeks from hell at the hospital.

We thought we made it through the worst of it but my father remained in hospital for another month and a half as he battled infections that kept coming back. However, my brother and I came across the CCA Facebook group and the other incredibly brave CCA fighters and supporting caregivers. We asked questions and looked for answers that we couldn't get otherwise. Forever thankful to every person who commented and provided us with information and resources. It was due to this that we are able to figure out how to stop the ongoing infections.

My father began his treatments of chemotherapy and immunotherapy in September 2024 and currently receives ongoing immunotherapy. He has also been treated with histotripsy, which has been incredibly impactful in his cancer journey. As a result of histotripsy, my father was able to eat and digest food better and gain back 11 kilos that he lost while hospitalized in the summer 2024. Everyone has complimented how much better he looks compared to pre-histotripsy.

I know the prognosis of this cancer isn't great, in fact, it's devastating. There will be absolute hard days, the bad days, the okay days and the good days and we manage each day as a family. However, I've switched my outlook into enjoying everyday with my father. I treasure every good moment he has and I don't take it for granted.

This is a long journey, one I don't wish upon anyone but one that has shown me resilience, strength, and advocacy as powerful tools to fight for my father's care and others facing the same uphill battle against this disease. I've learned that I'm not alone in this battle and I will continue to fight for my father and others needing access to support and resources.



My father thanks our family everyday for fighting for him but I tell him that I'm thankful to him for continuing to fight and never giving up because that takes real courage and strength.

#### **Board Updates**

The annual general meeting was held on August 16, 2025.

#### **Upcoming Webinars**

All of the webinars are posted on the website and YouTube channel. Check them out!

In August, 2025, Dr. Laura Dawson and Dr. Jennifer Knox held a webinar on SBRT for our patients and caregivers. It was an excellent informative session and well attended by patients and caregivers. The <u>link</u> to watch is here.

Dr. Howard Lim will be giving a webinar at 0900 PT (1200 ET) on Oct. 30. Further information will be sent out prior to that webinar.

# **Upcoming Dates:**

- Sept 2 Bereavement support group
- Sept 9 Canadian advocates meeting
- Sept 16 Patient support group
- o **Sept 21 –** Meet-up in Winnipeg
- Sept 23 French-speaking support group
- o Sept 24 Meet-up in Calgary
- Oct 7 Bereavement support group
- Oct 14 Canadian advocates meeting
- o Oct 19 Meet-up in Winnipeg
- Oct 21 Patient support group
- Oct 28 French-speaking support group
- o Oct 29 Meet-up in Calgary
- Oct 30 webinar with Dr. Lim
- Nov 4 Bereavement support group
- Nov 11 Remembrance Day
- Nov 16 Meet-up in Winnipeg
- Nov 18 Patient support group
- o Nov 25 French-speaking support group
- Nov 26 Meet-up in Calgary
- Dec 2 Bereavement support group
- Dec 9 Canadian advocates meeting
- Dec 16 Patient support group
- o Dec 21 Meet-up in Winnipeg
- Dec 23 French-speaking support group
- Dec 24 Christmas Eve
- Dec 25 Merry Christmas
- Dec 26 Boxing Day



# **Trivia Walk**

We are having an encore week for the trivia walk and it will run from September 21 through September 27, inclusive.

You can play by entering the following URL in your web browser: https://triviawalk.com/play If you don't have a course in your area, please contact us, and we will add a course for you!



# Play the Triviawalk



# **Education Corner**

# October is Liver Cancer month.

Some facts about liver cancer:

- o 6th most common cancer worldwide
- o 3<sup>rd</sup> leading cause of death
- o In 2022, over 866,000 new cases worldwide
- o In 2022, over 758,000 deaths worldwide
- o The biggest risk factor is chronic hepatitis B or C viruses
- AstraZeneca has a great informational page. Click on the link: <a href="https://www.astrazeneca.com/our-therapy-areas/oncology/Liver-cancer.html#">https://www.astrazeneca.com/our-therapy-areas/oncology/Liver-cancer.html#</a>!



Moncton City Hall (New Brunswick)



CN Tower (Toronto)

To support patient advocacy, <u>donate</u> here.

To volunteer with CHCC, please go to the "Contact Us" tab on our website (or click on the link) and message us.

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We would love to hear from you! Have a terrific autumn. Hopefully you can still enjoy the outdoors