



Welcome!

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

April 19 World Liver Day, 2025 “Light Up Green”

Facilities across Canada lit up green to raise awareness of this rare and aggressive cancer. Click on the link to see all the places that lit up green!

https://www.mychcc.ca/index.php?page=world_liver_day&lang=en&year=2025

Progress on Pemigatinib (Pemazyre) Coverage.

Pemazyre received a positive reimbursement recommendation. This is such exciting news for cholangiocarcinoma patients with the FGFR2 fusion mutation. Provinces are now in negotiations with the drug company for the cost through the pCPA.

Calgary CTV News coverage of the same:

<https://www.ctvnews.ca/calgary/article/a-chance-to-live-albertans-boosted-by-access-to-new-cancer-treatment/>

Kitchener CTV News coverage:

<https://www.ctvnews.ca/kitchener/article/ontarians-could-get-funded-access-to-new-rare-cancer-treatment-thanks-to-kitchener-ont-womans-advocacy/>

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

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 [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)



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

This is a FGFR2/3 inhibitor drug. The trial is currently open and they are just waiting for the next cohort to open. Our next meeting with the drug company that will let us know if we can put patients on takes place on Jun 19th. The oncologist sends the referral. One of the Phase 1 oncologists screens the chart to make sure at this time the person meets eligibility for the trial. Then the individual has to come to Edmonton for a consult and sign the consent. This cannot be done virtually; it is a mandatory in person visit. For more information contact Diane Arndt RN, BScN, Lead Nurse at (phone) 780-989-8157; (fax) 780-577-8138 or email at diane.arndt2@albertahealthservices.ca.

Tinengotinib access. Unfortunately, there are no clinical trials for this drug in Canada, which works for the FGFR2 fusion biomarker. Two Canadian patients are currently in Europe (Poland and Spain), participating in clinical trials there. Another patient is considering taking part in a clinical trial in the USA. If you wish to participate in the clinical trial in USA, please contact Priya Priyadarshini at priya.priyadarshini@syneoshealth.com.

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

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

Patient care kits

Thanks to AstraZeneca, Incyte and 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, and we're pleased to share that we've already sent out over 25 care kits! 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. Many thanks to the organizing committee, Neil Marr (chair), Mohammed Islam, Julie Davlut, and Brenda Clayton, who were the committee members. To volunteer, please visit our volunteer page on www.mychcc.ca. We look forward to working with both mentors and mentees.



Meet-ups across the country

Winnipeg - Meet up on third Sunday of every month at 10:30 AM at Stella's Bakery on Corydon. Contact manitobacca@gmail.com for more information.

Calgary – Meet up on the fourth 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 Cholangio-Hepatocellular Carcinoma Canada.

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

CCRAN's conference on Biomarkers 2025

Register for CCRAN's Biomarker conference in June.

It is free. If you miss any sessions, they will be available afterwards to those who signed up. The link is [2025 Biomarkers Conference Registration](https://www.ccran.ca/2025-Biomarkers-Conference-Registration)

CCF Annual Conference

This event took place from April 9 to 11. Everyone who attended was impressed with the knowledge offered, networking opportunities, and overall experience.

Register for the Canadian support groups by:

Go to www.mychcc.ca's website and the calendar of events (as shown in the screenshot below).

Click on 'contact us' for whichever group you want to join.

We will then send you a link.


Thanks in advance for registering.



OncoHelix Information

The biomarkers and associated CGP testing + cost is confirmed by OncoHelix.

The full 324 gene panel (tumour tissue) is \$2775 (CAD)



Comprehensive Genomic Profiling for Cholangiocarcinoma

Available testing and Cholangiocarcinoma associated targeted Biomarkers

OncoHelix-2 170 genes DNA Testing (powered by Illumina & Sophia Genetics)	FFPE	SNVs, Indels, CNVs, Fusions	\$1975
<div><div>● BRAF</div><div>● BRCA2</div><div>● FGFR2</div><div>● BRCA1</div><div>● ERBB2</div><div>● RET</div></div>	<div><div>● MSH2</div><div>● IDH1</div><div>● MSH6</div><div>● PMS2</div><div>● NTRK2</div><div>● NTRK3</div></div>	<div><div>● IDH1</div><div>● IDH2</div><div>● PALB2</div></div>	

● SNVs & Indels

● Copy Number Variations


● Known and Novel Fusions


OncoHelix-4 146 genes Liquid Biopsy (powered by MSK Access & Sophia Genetics)	cfDNA	SNVs, Indels, CNVs, Fusions	\$2575
<div><div>● BRCA1</div><div>● MSH2</div><div>● PALB2</div><div>● BRCA2</div><div>● MSH6</div><div>● PMS2</div></div>	<div><div>● BRAF</div><div>● RET</div><div>● ERBB2</div><div>● IDH2</div><div>● NTRK3</div><div>● NTRK2</div></div>	<div><div>● IDH1</div><div>● MLD1</div></div>	


1 Physician completes the OncoHelix Requisition Form.

2 OncoHelix will contact patient in 3 business days.


3 A genomic tumor profile report is sent to you 4 weeks after sample receipt.

 (403) 210-6974

 precision.diagnostics@oncohelix.org

 oncohelix.org

Access TRF



If you have any questions, please contact OncoHelix at the number or email address displayed.

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 info@mychcc.ca.



Dana Fox – A story of inspiration



[Ontario man runs Boston Marathon while battling stage 4 cancer - Canadian Running Magazine](#)

Board Updates

The annual general meeting is scheduled for August 16, 2025.

Teresa Holmes and Greg Siemens retired from the Board to focus on their growing family. We thank them for their hard work and dedication to helping found the charity and serve on the Board.

Two new Board members were appointed to the Board.

Welcome, Dr. Donald Holmes and Ambuj Srivastava.

Ambuj has a background in Engineering & IT and also serves as a Patient Advocate and Strategic Advisor with non-profits locally and globally volunteering his time with Ontario Institute of Cancer Research, Cholangiocarcinoma Foundation, Canadian Cholangiocarcinoma Collaborative, and Jarurat Care Foundation. As a former caregiver to his father with a rare form of cancer, cholangiocarcinoma, he understands the challenges for patients and families who endure this difficult journey. Ambuj is passionate about cancer research, patient advocacy and raising awareness by bridging the knowledge gap between patients, caregivers, and healthcare professionals.

Don has a medical background, having worked as a family doctor and then as a radiologist for more than 30 years. He is one of the founders of Cholangio-Hepatocellular Carcinoma Canada and also assisted as a former caregiver for his daughter, Rebecca Holmes.

We are excited to work with both of you in the future.



Upcoming Webinars

A nutrition webinar was held in May, and it was well received.

Click on the link:

<https://www.youtube.com/watch?v=rzdM3GvooU>

A cookbook, written by the Professors of Human Nutrition at the University of Alberta, was put together specifically for cancer patients. There are a lot of recipes to choose from. This [cookbook](#) is on the nutrition section of the website and can be downloaded.

<https://openeducationalberta.ca/proteincookbookforcancer/>

All of the webinars are posted on the website and YouTube channel.

Additional webinars are planned for this year. When the dates are confirmed, information will be sent to everyone.

Upcoming Dates:

- **June 12 – Global Fatty Liver Disease Day: Light up green!**
- **June 17 – CHCC support group**
- **June 22 – Meet-up in Winnipeg**
- **June 24 – French-speaking support group**
- **June 25 - Meet-up in Calgary**
- **July 8 – CHCC Bereavement support group**
- **July 20 – Meet-up in Winnipeg**
- **July 22 – CHCC support group**
- **July 23 – Meet-up in Calgary**
- **July 28 – World Hepatitis Day: Light up green (Hep B), Yellow and red (Hep C) and yellow and purple (Autoimmune Hep)**
- **July 29 - French-speaking support group**
- **Aug 5 – Bereavement support group**
- **Aug 12 – Canadian advocates meeting**
- **August 17 – Meet-up in Winnipeg**
- **Aug 19 – Patient support group**
- **August 26 - French-speaking support group**
- **August 27 – Meet-up in Calgary**
- **Sept 2 – Bereavement support group**
- **Sept 9 – Canadian advocates meeting**
- **Sept 16 – Patient support group**
- **Sept 21 – Meet-up in Winnipeg**
- **Sept 23 - French-speaking support group**
- **Sept 24 – Meet-up in Calgary**



Education Corner

Global Fatty Liver Day is June 12

The second Thursday in June is designated Global Fatty Liver Day. We have requested facilities across Canada light up green on this day to bring awareness to this 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). Even normal weight people may have this issue.

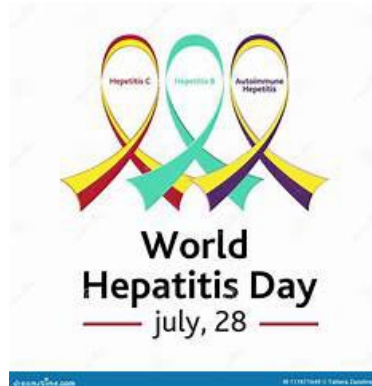
World Hepatitis Day is recognized on July 28.

[There are different types of hepatitis.](#)

Hepatitis is the leading cause of liver cancer. As well as the leading cause of liver cancer, hepatitis (especially Hepatitis B and C) is a common cause of cirrhosis of the liver and other viral hepatitis-related deaths. According to the World Health Organization (WHO), 354 million people globally live with Hepatitis B or C. Vaccination programs are available for Hepatitis A and B. There is no vaccination presently for Hepatitis C.

The colours for hepatitis awareness are green (hepatitis B), yellow and red (hepatitis C) and purple and yellow ([autoimmune hepatitis](#)).

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



Alzheimer's Disease

The FDA has approved a [blood test](#) to detect early Alzheimer's disease (AZ).

This doesn't affect CCA patients, but you may know someone who has AZ. This is in the United States, not Canada, yet.



Type 5 Diabetes

A new type of diabetes has been classified. [In April 2025, the International Diabetes Foundation declared type 5 diabetes an official type of disease.](#) Type 5 diabetes is different. It was first observed and described in Jamaica in 1955 but later dismissed. It is caused by malnutrition, leading to low insulin production. This malnutrition-related diabetes is believed to stem from impaired pancreatic development due to long-term nutrient deficiencies.

People with this form of diabetes have a profound defect in the capacity to secrete insulin and are on the thinner side of healthy IDF (2025). This leaves the body unable to make enough insulin to manage blood sugar properly. It is also referred to as “severe insulin-deficient diabetes” (SIDDD), characterized by elevated levels of insulin deficiency and poor metabolic control. Giving insulin is not appropriate and may cause hypoglycemia.

Type 5 Diabetes: Do you have the signs?

Type 5 diabetes is a newly recognised form of diabetes linked to malnutrition, not obesity.

It mostly affects young, undernourished people in low- and middle-income countries – and is often misdiagnosed.

Common symptoms include:

- Very low body weight or trouble gaining weight
- Constant tiredness or weakness
- Excessive thirst
- Frequent urination

- Blurred vision
- Muscle loss
- Poor appetite or trouble digesting food
- No response – or bad reactions – to insulin treatment

The condition is often inherited – if one parent carries the gene, their child has a 50 per cent chance of developing it.

Source: International Diabetes Federation (IDF), Albert Einstein College of Medicine, Christian Medical College India ■

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High-Level Bridge (Edmonton)



Niagara Falls webcam

To support patient advocacy, [donate](#) here.

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

We would love to hear from you! Have a terrific summer and enjoy the outdoors 😊