



Inspiring Hope Together

Welcome	2
Light It Green campaign	2
Clinical Trials	3
BiomarkerHelp.com	4
Patient Care Kits	4
Mentorship Program	4
Meet-ups across the country	4
Register for Patient Support Groups	5
Patient Story Corner	6
Recent Webinars	11
Upcoming Webinars	11
Education Corner	11
Well Spring Canada	11
Upcoming Dates	11



Inspiring Hope Together

Welcome!

Welcome to the first issue, volume 3 (2026) of the Cholangio-Hepatocellular Carcinoma Canada (CHCC) newsletter.

“Light it green” campaign on Feb 19, 2026

The following posters were approved by the committee members from CHCC and C3 for Light it green in February. The slideshow can be watched using this [link](#). Or [view the event page](#).



Thanks to Corri Desaulniers for providing this poster!



Thanks to Leonard Angka and C3 for providing this poster!



Inspiring Hope Together

Recommend reimbursement with conditions for Nivolumab Plus Ipilimumab (Opdivo Plus Yervoy)

Read more [here](#). This is for liver cancer.

Clinical trials that are happening across the country

**Go to clinicaltrials.gov for any worldwide trials using this [link](#).
Or try the Cancer Trials Canada [link](#).**

Clinical trials that are happening across the country

All-comer trials in HCC or BTC:

ARTEMIDE-HCC01 AstraZeneca

Click [link](#) here for details.

Currently, Toronto is the only Canadian site that is recruiting.

ARTEMIDE-Biliary01 AstraZeneca: after resection: Active, not recruiting

Biomarker-specific Clinical Trials

IDH-1 biomarker: Tibsovo (ivosidenib) Servier: NO longer recruiting.

If you have the IDH1 biomarker, contact mychcc.ca and you can obtain further information about ivosidenib.

**HER2 expressing tumours: Trastuzumab deruxtecan (T-DXd) AstraZeneca:
NO longer recruiting.**

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

Click on the [link](#) here for more details.

NCT06467357

Phase 3 trial in HER2+ BTC Jazz Pharmaceuticals

An Open-label Randomized Trial of the Efficacy and Safety of Zanidatamab With Standard-of-care Therapy Against Standard-of-care Therapy Alone for Advanced HER2-positive Biliary Tract Cancer.

Recruiting in 3 sites: Toronto (PMCC), Montreal, and London.

Click [link](#) for more details. NCT06282575

CLARITY-PanTumor01 AstraZeneca for tumours expressing Claudin 18.2 biomarker

Click on [link](#) here for more details.



Inspiring Hope Together

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](https://clinicaltrials.gov/ct2/show/study/NCT06764316) (click on hyperlink)

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

NCT06777316 Click here for the [link](#).

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 diane.arndt2@albertahealthservices.ca

Tinengotinib access. *The success of Tinengotinib is on this [link](#). If you have been on Pemigatinib and it is no longer working, contact Jenna Blamowski*

Jenna.Blamowski@RoswellPark.org or Christos Fountzilas

Christos.Fountzilas@RoswellPark.org

website: <https://www.roswellpark.org/clinical-trials/list/5354>

BiomarkerHelp helps you find personalized options to fight cancer – for free. Simply upload your biomarker test report. Their focus is on YOU – they don't partner with anyone for profit. This is a change from genomic focus. It is run by Matt Reidy. **BiomarkerHelp** has a clinical trials map that will show any clinical trials that match your tumor biomarkers.

BiomarkerHelp's website: <https://biomarkerhelp.com/>

Patient care kits

Thanks to AstraZeneca, Incyte, Merck, and two local dentist's office in Red Deer and Edmonton, 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 click on this [link](#).

Mentorship program

CHCC has a mentorship program that provides 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 click on this [link](#). 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.)

Victoria/Vancouver - Meet ups are at 11:00 am on the last Sunday via Zoom. Contact mychcc.ca if you would like more information.

Winnipeg – Meet-ups on hold



Inspiring Hope Together

Calgary – Meet up on the last Wednesday of every month. As of January 2026, the venue will be changing monthly as the patient group wishes to try different venues across the city. Everyone is welcome to attend either meet-up. If anyone requires more information go to [Cholangio-Hepatocellular Carcinoma Canada](#).

Register for the Canadian support groups

To register, please click on the following links:

- Bereavement Support Group ([Register](#))
- Canadian Advocates Meeting ([Register](#))
- Patient Support Group ([Register](#))
- French Support Group ([Register](#))

Thanks in advance for reaching out.

Register for the upcoming CCF conference in May 2026

Click on the [link](#) to register for the conference May 1-3, 2026 in Salt Lake City.

Register for the upcoming AMMF European Cholangiocarcinoma conference in May 2026.

Click on this [link](#) to register for the conference in UK on May 12-15, 2026.

Register for the 2026 CCRAN Biomarker Conference June 18-19, 2026

Click on this [link](#) to register.

Biomarker testing

As of December 31, 2025, C3 will not be covering the cost of the biomarker testing. Information for your physicians can be obtained from C3 or [CHCC](#). The cost is approximately \$2000 -\$2200.

OncoHelix-2 is transitioning to OncoHelix-3, our next-generation genomic profiling assay expanding coverage to 523 clinically relevant genes, including **integrated immuno-oncology markers such as MSI, TMB, and HRD**.

All variants previously detectable with OncoHelix-2 remain fully covered in OncoHelix-3, with additional genomic insights applicable across solid tumours. Please find attached the information sheet with details, including information about **financial assistance and the updated test requisition form for your reference**.

To support implementation, introductory pricing of **\$1,775 CAD (tax-free)** will be available until the end of March. We invite you to review the attached materials and consider OncoHelix-3 with the expanded capabilities for your community.



OncoHelix-3
Information Sheet.pdf



OHL#TRFM002
Oncohelix-Genomics_I



Inspiring Hope Together

Funding review (HTA submission) expected for Ivosidenib in May/June

Have you or your loved one been treated with ivosidenib (Tibsovo)? Ivosidenib (Tibsovo) is used in the treatment of CCA patients with the IDH1 mutation. Patients and/or caregivers who have experienced treatment with Tibsovo (ivosidenib) are invited to participate in a confidential telephone interview to share their perspective on cancer care and treatment. Please contact tibsovo@mychcc.ca to arrange a time.

Update to Pemigatinib in Cholangiocarcinoma

Pemigatinib for the treatment of adults with unresectable locally advanced or metastatic cholangiocarcinoma (CCA) with a FGFR2 fusion or other rearrangement. Patients must have received at least 1 line of prior systemic therapy and have good performance status. Pemigatinib should be continued until disease progression or unacceptable toxicity. Patients who are intolerant to, but have not progressed on, first-line treatment may receive Pemigatinib provided they meet criteria.

The provinces that now have Pemazyre on the formulary are:
QC, NB, NS, SK, AB and BC.

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.

NB's story as told by his wife NC

NB first experienced unusual abdominal pain on April 8, 2024 — a date he remembers clearly because it was the day of the solar eclipse. The pain returned in the following days and weeks, raising concern.

Living in Quebec without a family doctor, NB was considered an “orphan patient,” which made access to primary care more complicated. At the time, he needed an appointment to renew his medications, and he planned to also discuss his new symptoms. During that appointment, his prescriptions were renewed, but when he tried to discuss his abdominal pain, he was told that only one issue could be addressed per visit, and his concerns were therefore not evaluated.

The following day, he went to the emergency department. His condition was not considered urgent, and he was redirected to a clinic appointment two days later. He was prescribed basic blood tests and medication for digestion. The tests came back normal, and the pain persisted.

Later that summer, another physician ordered a liver ultrasound and liver function tests. Due to the lack of continuity of care, it took time to receive results, which were reported as



Inspiring Hope Together

normal. His digestive medication was increased, and a gastroscopy was ordered, but he was never contacted for the procedure.

A few weeks later, NBs' symptoms worsened significantly. He developed jaundice and dark urine. He returned to the emergency department, where he received the diagnosis: stage IV metastatic Klatskin cholangiocarcinoma — inoperable and incurable. NB was 45 years old at the time.

Biliary stents initially failed to relieve the obstruction, and his condition deteriorated rapidly. He was hospitalized for two months while doctors worked to drain his liver, eventually placing three external biliary drains — an exceptional and complex intervention. It was not until December 18, 2024, that his bilirubin levels finally stabilized enough for him to begin first-line treatment.

Since then, NB has faced this diagnosis with remarkable courage, resilience, and hope. In the fall of 2025, NB and I participated in several media interviews to raise awareness about the importance of timely access to primary care and accurate diagnosis.

In November 2025, despite his illness, NB completed what he calls his “last expedition” — a 30-kilometre backcountry trek with loved ones. This journey became the documentary *My Last Expedition*, which shares his story, his values, and his message about living fully, even in the face of terminal illness.

In January 2026, NB became an ambassador for OQPAC, a Quebec organization supporting people living with cancer and their families.

Today, NB continues to advocate for cholangiocarcinoma awareness. This rare and aggressive cancer remains critically underfunded and offers very limited treatment options. Through advocacy, public speaking, and awareness campaigns, he hopes to help improve research funding, early detection, and patient support.

NB also continues to pursue meaningful life projects and challenges, including planning a charity rappel descent from the Château Frontenac to raise awareness about cholangiocarcinoma. The event is expected to receive television media coverage, helping bring greater visibility to this rare and under-recognized cancer.

Our goal is simple: to help people understand this disease, support research, and remind others how precious time and quality of life truly are.

AL's story and his tribute to World Cholangiocarcinoma Awareness Day which was on February 19, 2026.

The year 2003 in Toronto was particularly eventful. In February, SARS, the precursor virus of [COVID-19](#), emerged. I once snuck into the Hummingbird Centre, now called Meridian Hall, with my friends to see an opera. I remember wondering if anyone in the room had this

*Inspiring Hope Together*

virus. Doctors and nurses in the city were dropping like flies. In August of that year, I worked as an intern at an advertising agency and a power outage paralyzed the city for three days. I lived at 18^e floor. In November, when I was in my final year of my bachelor's degree, Denys Arcand released his film *Les invasions barbares*. It should be remembered that this film revealed an unflattering facet of the Quebec medical system, in the middle of which a suffering patient had to make peace with his imminent death.

A few months later, when the film was released in Buenos Aires, my father told me that neither he, nor his friends, nor anyone else for that matter could believe it. In Argentina, it was normal, but in a rich country of the first world? *The Barbarian Invasions* was released more than 20 years ago. Things haven't changed much, except that it's no longer Rémy Girard who has to die, but me.

Let me tell you who I am and what I do, because very few of you probably know. I was born in Argentina 46 years ago. I grew up there, the first four years under a dictatorship, the rest under democracy, and I studied there. I was 7 years old when my mother died in a car accident that my grandparents, sister and I survived. Despite this life-changing event, I think I had a happy childhood, surrounded by a family that loved me and took great care of me.

Nevertheless, at the age of 21, the time had come for me to leave this inexplicable country of the South where crises and generational exiles are cyclically repeated every decade. I chose Canada. In 2008, I finally moved to Montreal, where I have made most of my work as a documentary filmmaker. In fact, my new film, *Les blues du bleuét*, will be shown throughout Quebec starting February 27. Go see him! It will probably be my last.

As it happens, in April 2025, I was diagnosed with cholangiocarcinoma, a rare and aggressive cancer of the bile ducts. This little-known cancer is difficult to treat and has only a poor prognosis.

When playing chess with death, you need to know the rules of the game well. Alas, I've never been very good at board games. I am not going to go into the details of the twists and turns in the Quebec health care system over the past year. I am of course extremely grateful to the medical, nursing and other health care staff who take care of me, often with kindness.

However, learning to live with a disease that is a Formula 1 champion in a system that moves at 10 km/h is an experience that is "difficult" at best and "Kafkaesque" at worst. I wish I had known what I know now when the first symptoms appeared a year and a half ago. There are as many *patches* in this system as there are potholes in the streets of Montreal.

I still have a bit of hope in my pocket: in August 2025, it was discovered that my tumour had an amplification of the HER2 protein, for which there are other targeted therapies to try. Will I be able to access it? Will they be effective, and for how long?



Inspiring Hope Together

I hesitated a lot before telling you all this, because the desire to go through this disease in peace is stronger than my desire to expose myself. I've always preferred to be behind the camera. I never dreamed of being an influencer. I prefer to be talked about my films rather than my illness. But hey... Everything is going so fast that I don't know if I'll still be here next year. Sharing this experience, I tell myself, may help other people.

February 19 marks World Cholangiocarcinoma Day. One of the main problems with this disease is the lack of visibility and, therefore, the lack of funding for research. Organizations such as the Canadian Cholangiocarcinoma Collaborative or Cholangio-Hepatocellular Carcinoma Canada are invaluable in supporting the affected community and helping to advocate for needs by advocating for resources, more research, and better access to targeted therapies. The more we raise awareness of this disease, the more opportunities we will open up for early diagnosis, more effective treatments, and a brighter future for all those affected.

I invite you to inquire, to make a donation to one of these organizations, and I ask you to taste myriads of wild blueberries for my health.

CD's story

My name is CD. I'm 46 years old, a wife, and a mom to two teenage boys. My story with cholangiocarcinoma began in the fall of 2021. I went to the ER with stomach pain, assuming it was something routine. I was scheduled for gallbladder surgery, but during pre-surgical imaging, doctors found a mass on my liver. And just like that, everything shifted.

In early February 2022, after months of additional testing, waiting and multiple visits to the local ER for pain, I was scheduled for an appointment at a cancer centre. At the appointment, I was given a survey to take pertaining to cancer patients along with cancer relevant materials to read. Keep in mind that no one had told me I had cancer at this point. I don't know of a better way to handle these appointments, but I can assure you that this was not it. My husband and I finally met with the surgical oncologist where the words, You Have Cancer were said.

In May 2022, I underwent a partial liver resection to remove what we were initially told was a neuroendocrine tumor. I went home with clean margins and cautious optimism, hoping the surgery would be the end of it. The final pathology from the liver resection confirmed it was actually cholangiocarcinoma — a rare and aggressive bile duct cancer. That was the true beginning of this chapter.

Starting in August 2022, after a few months of recovery, I began eight rounds of adjuvant capecitabine, doing everything possible to reduce the risk of recurrence. Despite that, early 2023 scans showed the cancer had metastasized to my peritoneum. I was given a very grim prognosis. As a mom and a wife, that's not something you ever feel ready to hear.



Inspiring Hope Together

We moved quickly into treatment. Between April 2023 and August 2024, I went through multiple lines of therapy: gemcitabine, cisplatin, and durvalumab; maintenance durvalumab; and later FOLFOX. Each new regimen came with renewed hope, and each time, eventually, the scans showed progression. By mid-2024, I was told that there were no other proven treatments for my type of cancer. I didn't qualify for any available clinical trials and there were no surgical options available in Canada. The original molecular testing done on my liver tumour had not shown any targetable mutations. My time left on this earth could be 6 months or less.

It was one of those conversations that changes you. That moment marked a turning point. I wasn't ready to accept that there was nothing left. At my lowest point, an unofficial mentor encouraged me to connect with the Canadian Cholangiocarcinoma Collaborative, known as C3. That connection changed everything. In partnership with C3, we pushed for comprehensive molecular testing on my peritoneal tumors — not just the original liver tumor. That testing revealed an FGFR2 fusion, something that had not been present in the initial panel. For the first time in a long time, there was a new door to open.

That mutation made me eligible for a targeted therapy called Pemigatinib. The drug was not yet publicly funded in Canada, and accessing it required exceptional approval. With the support of my oncologist and C3, I was granted access and began treatment in December 2024.

Since then, quarterly scans have shown overall stability, no new tumours and even some tumour shrinkage. For the first time in a long while, we had good news. Pemigatinib has not been easy. The fatigue is real. My appetite disappeared. I've experienced significant weight loss, hair loss and nail toxicity. Living with ongoing treatment means constantly balancing hope with side effects, and learning how to support my body in new ways. But I am here. And right now, it is working.

My experiences have fundamentally changed how I see my role as a patient. I have realized that information matters. Access matters. Molecular testing matters. Community matters. And not everyone knows what to ask for.

If I hadn't been nudged toward further molecular testing, I may never have discovered that I had an actionable mutation. Advocacy, for me, was never about standing on a stage. It was about survival. It was about asking hard questions, pushing when something didn't feel complete, and making sure other patients know they can do the same.

Cholangiocarcinoma is rare. Many patients are misdiagnosed or diagnosed late. Treatment options can be limited. But precision medicine is changing the landscape — if patients have access to comprehensive testing.

I did not choose this disease. But I can choose what I do with it.



Inspiring Hope Together

Today, advocacy is part of how I cope. It gives purpose to something that once felt completely out of control. Whether I'm sharing my story in a webinar, encouraging patients to ask about comprehensive molecular testing, supporting fundraising efforts that expand access, or simply reminding someone they are not alone — this is how I fight back.

If sharing my story leads even one person to ask about molecular testing...

If it helps one family find hope through precision medicine...

If it brings one more person into this community...

Then it is worth it. ❤️

Editor's note: *We thank you all for sharing your stories. You are all courageous in your outlook. Thank you for your contributions to raise awareness for cholangiocarcinoma and advocating for patients with CCA.*

Recent Webinars

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

Dr. Maureen McColl held a webinar on January 29 to learn more about WellSpring. It was very informative and well attended by patients and caregivers. The [link](#) to watch is here.

Dr. Brandon Meyers hosted a webinar on Mar 5. The [link](#) to watch is here.

Upcoming Webinars

Jessica Anderson RD will host a nutrition webinar in May. Date TBA.

Education Corner

WellSpring Canada is an organization for all cancer patients. It has a physical presence in Alberta, Ontario and New Brunswick with online availability Canada-wide.

The programming is evidence based. They have paid professional facilitators, and it is offered at no cost to the patient. To register, go to www.wellspring.ca Once you become a member, you can sign up for any online courses that are offered. It is a great organization and worthwhile checking it out!

Upcoming Dates:

- **Mar 17** – Patient support group
- **Mar 24**- French-speaking support group
- **Mar 25 – Calgary meet-up** (contact CHCC has the venue is changing)
- **Apr 7** – Bereavement support group
- **Apr 14** – Canadian advocates meeting
- **April 19 – World Liver Day**
- **Apr 21** – Patient support group



Inspiring Hope Together

- **Apr 28** - French-speaking support group

- **May 5** - Bereavement support group
- **May 12** – Canadian advocates meeting
- **May 19** – Patient support group
- **May 26** - French-speaking support group
- **May 27 – Meet-up in Calgary**

- **Jun 2** – Bereavement support group
- **Jun 9** – Canadian advocates meeting
- **Jun 11 – Global Fatty Liver Day**
- **Jun 16** – Patient support group
- **Jun 23** - French-speaking support group
- **Jun 24 – Meet-up in Calgary**

Light It Green Venues across Canada



PEI Shaw Centre



Marche Public Jean-Talon, Quebec City

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! We are just a text, email or phone call away. We are always available if you need to reach out.