

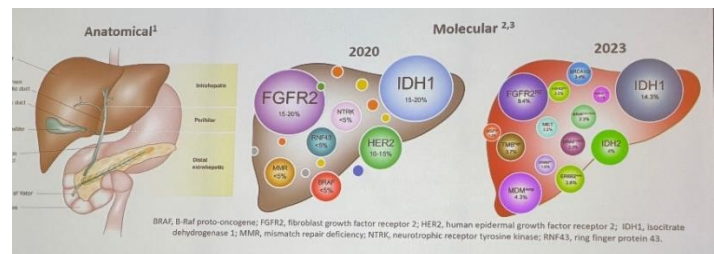


## Cholangio-Hepatocellular Carcinoma Canada Newsletter Volume 1, December 2024

### Welcome!

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

### Cholangiocarcinoma Foundation symposium in Houston



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A few Canadians attended the symposium in Houston in December. An update on identified biomarkers was just one of the topics. A wealth of knowledge was presented!

### Slogan

In the last issue, CHCC asked for input into a catchy slogan. In addition to the ones suggested, we received a couple of other suggestions. We ask once more for your vote.

Here are some suggestions given to us:

- Growing Hope Together
- Building Hope Together
- Helping Hope Grow
- Growing Hope and Advocacy Together
- Inspiring Hope Together

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

### Progress on Pemigatinib (Pemazyre) Coverage.

**October 18, 2024** - In response to all the advocacy from the nine organizations and individuals, the Canadian Drug Agency (CDA) requested a resubmission from patients, clinicians, and the drug company Incyte. The date for this was December 13, 2024. By the time this newsletter goes out, the patient story submissions will have been submitted. Thank you to everyone who contributed to this application. Efforts to have the provinces cover patients while the CDA and then pERC review the



submissions are ongoing. In addition to Quebec and Alberta, who are already covering reimbursement, Ontario, Nova Scotia, and Manitoba are now covering Pemazyre on a case-by-case basis until the ruling regarding the recommendations occurs in March or April 2025. We continue to approach British Columbia and other provinces for coverage. We will keep you informed of the submission results.

A CTV News story regarding Pemazyre:

<https://calgary.ctvnews.ca/promising-treatment-gives-fresh-hope-to-patients-with-rare-deadly-cancer-1.7101285>

### **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, which occurs in both intrahepatic and extrahepatic CCA. As of October 25, 2024, Servier (the supplier) has obtained a supply of drugs for Canada. A patient support program (PSP) is available to cover part of the cost for patients who do not have drug plans. Clinical trials for ivosidenib are also occurring in Canada.

### **Patient care kits**

Thanks to AstraZeneca, patient care kits are available for new patients diagnosed with either cholangiocarcinoma or hepatocellular carcinoma. I am pleased to share that we have mailed out 6 care kits already!

If you know anyone newly diagnosed or without a patient kit, please contact [newsletter@mychcc.ca](mailto:newsletter@mychcc.ca).

### **Mentorship program**

A CHCC committee has been formed and will meet in January to start work on a mentorship program for patients and caregivers. If anyone would like to join the committee, please email Brenda at [newsletter@mychcc.ca](mailto:newsletter@mychcc.ca), and we will include you in the committee Zoom call.

### **Cancer interview with Cynthia**

YouTube video with Cynthia, cholangiocarcinoma warrior, on sharing the journey. Click on the link for more information.

<https://www.youtube.com/watch?v=pdFG5IUtqJE>

### **Living a Life of Joy Despite Stage 4 Cancer**

Listen as Cynthia describes her decision to live her life purposefully, even with stage 4 cholangiocarcinoma. There is only time to live a joyous life!

Click on the link for more information.

<https://www.youtube.com/watch?v=ms8jRMs7C8>



### **Patient Voice**

Another article about a patient's journey so far:

[The dawn of a new era for Canadians living with cholangiocarcinoma.](#)

Click on the link for more information.

Here's an excerpt:

*In the lush foothills south of Calgary, with the Rockies towering at her doorstep and her husband, rescue dogs, and horses at her side, Jennifer Nielsen is planning to live a good long time. At 56, she can easily picture herself still strong and vibrant at 90. There's only one thing standing in her way: a rare, aggressive form of biliary tract cancer. Jennifer, however, is certain that cancer is just one chapter in the story of her life. And there's a lot of book left to write.*

### **Article About and Ontario Patient**

Follow this link for the story:

[Cancer patient's victory over meds highlights battle over what drugs are covered under OHIP](#)

Here's an excerpt:

*A Newmarket woman suffering from a rare cancer is thrilled the provincial government has finally agreed to pay for her needed medication.*

### **CCF Annual Conference**

Patients in Canada who are interested in attending the annual Cholangiocarcinoma Foundation conference can apply for a scholarship. This is for patients only; caregivers must cover their expenses if they want to accompany a patient who is approved for a scholarship.

Click on the link to apply.

<https://cholangiocarcinoma.org/annual-conference/patient-scholarship-application-form/>

### **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. If you would like to submit your story, please get in touch with [newsletter@mychcc.ca](mailto:newsletter@mychcc.ca).

### **T and R's story**

*In April 2023, T and I returned home from our annual winter escape to Portugal. Shortly after, T began feeling unwell, prompting a visit to his family doctor. A series of tests revealed a mass on his liver. We were devastated to learn that it was likely stage four cholangiocarcinoma.*



*T was referred to Dr. Veitch, an oncologist at RVH Hospital in Barrie, who recommended a treatment plan involving chemotherapy and immunotherapy. While discussing options, Dr. Veitch informed us about a promising drug, Pemigatinib, available in Canada but not yet covered under government healthcare. Pemigatinib specifically targets the FGFR2 fusion gene mutation, which T's cancer carried.*

*Determined to explore every option, our family decided to advocate for T and all Canadians facing similar battles. Starting in November 2023, we mobilized friends, family, and community members to write letters, send emails, and contact local, provincial, and federal government officials. We also reached out to media outlets, sharing T's story on television and in newspapers to raise awareness about the urgent need for access to this drug.*

*At one point, when conventional treatments reached their limits, T signed up for the Medical Assistance in Dying (MAID) program, fearing he was out of options. However, our son M refused to give up. Inspired by his determination, we pushed harder along with daughter S, continuing our advocacy with even greater resolve.*

*Our hard work paid off. T was approved for Pemigatinib coverage. Since starting the drug, T's transformation has been remarkable. His energy has returned, his appetite is strong, his blood work has improved, and he looks and feels like himself again. We are overjoyed and beyond grateful.*

*While we celebrate this victory for T, we are acutely aware that the battle for equitable access to cancer treatments is far from over. Pemigatinib should not be an exception; all Canadians with FGFR2 fusion-positive cholangiocarcinoma deserve access to this life-changing drug.*

*T's journey highlights how critical it is to advocate relentlessly for your loved ones. Our family's experience shows that persistence, collaboration, and public awareness can lead to meaningful change. To anyone navigating similar challenges, we urge you to keep fighting, keep advocating, and never give up hope.*

Sincerely,  
R

**Updates from patients from previous newsletters:**

**MC's Update:**

*After 14 months of taking Erlotinib for my ERRF11 mutation, my disease remains stable!*

*This past August, my team and I decided to pursue radiation therapy as a next step. I travelled to Toronto to have SBRT on my remaining three liver lesions. All went well, and we are closely monitoring my liver to see how the cancer is responding.*



*This targeted therapy is not only keeping my disease stable, but it has also given back my quality of life, which has allowed me to put more energy into awareness and advocacy efforts, as well as patient mentoring. The connections I have forged over the last year have added a richness to my life and the research and advancements in care are giving me HOPE for the future.*

*The work of CHCC continues to change the landscape for Canadians with Cholangiocarcinoma- thank you!*

### **JN's Update**

*I am just giving a quick update since the beginning of September 2024, when my chemotherapy (cis/gem/durva) treatment plan was stopped. My 7 months of chemotherapy was no longer working as my tumors in my lungs, liver and lymph nodes had grown and my kidneys were struggling.*

*I started Pemigatinib September 30, 2024 and had my first CT Scan November 20th. I can happily report my tumours are showing a good 25% decrease in all areas. My strength and appetite is coming back now that I am off chemotherapy. I have a few side effects from Pemigatinib. Mainly, very dry skin and eyes. Random sharp abdomen pain, that decreases on my week off the meds. Bone pain, that seems to migrate to different joints.*

*Overall, my energy level has increased significantly, and my blood work numbers are all near the normal range—a marked change from being on chemotherapy.*

*I also saw Dr. Carey Johnson, a geneticist in Calgary, who was very knowledgeable and helpful about future gene testing or options I should pursue regarding biomarker testing. I highly recommend finding a specific doctor of genetics to understand all the options available.*

*Sending out positive energy and strength to all. Stay in the light, as a win can be just around the corner.*

*Take care,  
JN*

### **Upcoming Dates:**

- **January 7, 2025** – CHCC Bereavement support
- **January 21** – CHCC support group
- **February 4** – CHCC Bereavement support
- **Feb 18** - CHCC support group
- **Feb 20 – World Cholangiocarcinoma Awareness Day  
Light Up Green Campaign**
- **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  
**Patients - don't forget to apply for a scholarship to attend**
- **April 15** – CHCC support group
- **April 19 – World Liver Day**  
**Light up green**

### **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 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).



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.

**We want to take the time to remember everyone who has been a part of the charity this past year.**

**Christmas and holidays can be challenging times to celebrate.**

**Thank you for allowing us to be a part of your lives.**

**We wish you all the best this Christmas season.**

***Love and Hugs from: Everyone at Cholangio-Hepatocellular Carcinoma Canada***