



Canadian
Cancer
Society



Rare cancers.

The difference you are making.

Rare cancers affect fewer people individually, but together they represent a significant—and often overlooked—burden for patients, families, and health systems.

Through targeted investment and collaboration, Canadian Cancer Society (CCS)-supported researchers are advancing understanding of these complex diseases, improving diagnosis, and opening new paths to treatment where few options once existed. This report highlights how research into rare cancers is turning scientific insight into real-world impact, offering hope to communities that have long been underserved.

Accelerating progress and providing hope to people living with biliary tract cancer.

A team led by Dr Carolina Ilkow and Dr Rebecca Auer is expanding access to clinical trials and personalized treatments for people with biliary tract cancers (BTC), accelerating progress and providing hope to people with this devastating disease.

Biliary tract cancers (also called cholangiocarcinomas) although rare, are the second most common liver cancer. They have an alarmingly low survival rate and there are few treatment options available to those facing BTC. Most people are diagnosed in Stage 4, when surgery is no longer an option and chemotherapy may extend the duration of life but take a significant toll on its quality. There is an urgent need for new and innovative treatments for people with BTC, and immunotherapy has shown promising results.

With support from CCS and the Canadian Institutes of Health Research, a world-class team of experts across Canada will establish the Canadian Cholangiocarcinoma Collaborative (C3). This first-of-its-kind partnership between people with cancer, caregivers, clinicians and scientists will aim

to provide new treatment options and establish a national registry for people with BTC. The C3 will also boost access to clinical trials and provide opportunities for participation through a national referral network. The C3 will develop and manufacture the first-in-Canada personalized T cell product to offer hope for Canadian patients with BTC and establish an immunotherapy pipeline for innovating novel therapies.

This targeted and collaborative approach will provide equitable access to new treatment options that are rarely accessible in Canada and, if successful, would significantly enhance survival and quality of life for people with biliary tract cancer.



Dr Rebecca Auer



Dr Carolina Ilkow

IT TAKES A SOCIETY

1-888-939-3333 | CANCER.CA

Thelma Kelly's story.



In January 2023, while vacationing in Florida, a CT scan during an emergency room visit revealed a 9.5 cm tumour in Thelma Kelly's liver. Determined to act quickly, Thelma and her husband Harold returned home with the scan, as well as results from blood tests and an MRI. A follow-up blood test for cancer markers showed high CA 19-9 levels – a strong indicator of cholangiocarcinoma, a cancer that, although rare, is the second most common liver cancer. Not long after, a biopsy confirmed the diagnosis.

The news was devastating. Thelma and Harold felt hopeless, spending hours online searching for answers they never found. The first year was marked by tears, uncertainty and exhausting chemo cycles. Added to this was the stress of frequent travel from their rural community to St. John's for treatment. Harold took on the role of advocate, researcher and constant companion. He managed Thelma's care, attended every appointment, and pushed for advanced options.

In the following months, the couple navigated many setbacks and small victories. Thelma began chemotherapy in April 2023. After 16 treatments over 6 months, a CT scan showed that the tumour had shrunk by half – but also found a new lesion on her spine. Thelma received radiation out of precaution, but this finding meant that her cancer was classified as metastatic, ruling out surgery. By April 2024, following 6 months of immunotherapy treatment, the tumour in her liver had grown again, so she resumed chemotherapy. After 18 more treatments, an October scan showed that the tumour had shrunk once more while the spinal lesion remained unchanged.

During this time, Thelma and Harold connected with the Canadian Cholangiocarcinoma Collaborative (C3), which led to a review of Thelma's case by a panel of expert oncologists across Canada who suggested that the spinal lesion might not be a metastasis. A PET scan later confirmed this, allowing Thelma to undergo liver resection surgery in January 2025.

Unfortunately, a CT scan in mid-2025 showed that, despite complete clearance from the liver, Thelma's cancer had metastasized to her lungs. As of a January 2026 CT scan, the lung lesions – all only a few millimetres in size – are shrinking. One year since Thelma's liver resection, there are no signs of disease, damage, tumours or significant abnormalities detected in her liver. Thelma now is taking a break away from chemo after a total of 50 chemo treatments in 3 years.

Despite the rollercoaster of challenges, Thelma and Harold found strength in each other and in the community of family, friends, researchers and others facing this disease who rallied around them, especially C3. They remain focused on living life fully by travelling, staying active and spending time with family. Together, they are now mentors for others with cholangiocarcinoma, sharing their experience and offering the hope and strength they found to patients just starting treatment.



Thank you.

Your generosity fuels research where the need is greatest—advancing discovery, accelerating new treatments, and bringing hope to patients and families who are too often overlooked. Together, you are helping transform scientific promise into real-world impact. Because nothing big in cancer gets solved by one person or one organization. It takes all of us. It takes a society.