

CCF Facts:

Research

Since 2015, CCF has invested more than \$6.4 million in research to better understand this complex disease and accelerate finding a cure.

Research Fellowship Program

CCF’s Research Fellowship Program provides funding for innovative, high-impact research to early career researchers focused on cholangiocarcinoma.

Komodo Partnership

CCF offers an online specialist map for patients in the United States that is powered by Komodo Health Data. This data is also used to explore the incidence and prevalence of cholangiocarcinoma.

Biomarkers Matter Initiative

Biomarker testing is important for every cholangiocarcinoma patient. 50% of patients have a targetable treatment option which can only be accessed with appropriate biomarker testing. Scan the QR code to learn more or visit *biomarkersmatter.org*.



ICRN

CCF launched the International Cholangiocarcinoma Research Network (ICRN), a global collaboration of more than 200 physicians and scientists from 108 cancer centers in 19 countries, who work in concert to improve knowledge about cholangiocarcinoma etiology, prevention, early detection, treatment, and prognosis. ICRN facilitates multi-center basic, translational, and clinical research to ensure rapid translation from bench to bedside. To view our current member institutions, please scan the QR code, or visit *icrn.cc*.



website:



[curecca.org](http://curecca.org)

social media:



[facebook.com/\*cholangiocarcinoma\*](https://facebook.com/cholangiocarcinoma)



[twitter.com/\*curecc\*](https://twitter.com/curecc)



[instagram.com/\*cholangiocarcinoma\*](https://instagram.com/cholangiocarcinoma)



[youtube.com/c/ \*cholangiocarcinomafoundation\*](https://youtube.com/c/cholangiocarcinomafoundation)



[linkedin.com/company/\*cholangiocarcinoma-foundation\*](https://linkedin.com/company/cholangiocarcinoma-foundation)



[tiktok.com/\*@cholangiocarcinoma\*](https://tiktok.com/@cholangiocarcinoma)



[bsky.app/profile/\*cholangiocarcinoma.bsky.social\*](https://bsky.app/profile/cholangiocarcinoma.bsky.social)



[threads.com/\*@cholangiocarcinoma\*](https://threads.com/@cholangiocarcinoma)

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Cholangiocarcinoma  
Foundation®

our mission is to find a cure and improve the quality of life for cholangiocarcinoma patients

## who we are

Founded in 2006, the Cholangiocarcinoma Foundation is a global 501(c)(3) nonprofit organization. Its mission is to find a cure for cholangiocarcinoma and improve the quality of life for patients. It achieves this mission by supporting basic and translational research and raising awareness in the cholangiocarcinoma community through advocacy, education, and collaboration.

## what we do

Everything that CCF does is with patients and caregivers in mind. Their welfare is the number one priority that drives focused efforts on supporting basic and translational research and raising awareness about cholangiocarcinoma. The Foundation is driven by four core values.



Patients First



Collaboration



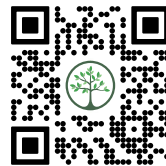
Innovation



Urgency

## how we can help

CCF provides patients and caregivers with information about cholangiocarcinoma, treatment options, clinical trials, specialists, support, nutrition, and much more. Newly diagnosed patients can register to receive a free care kit to support them on their treatment journey. Scan the QR code to learn more or visit [cholangiocarcinoma.org/newly-diagnosed](http://cholangiocarcinoma.org/newly-diagnosed)



CCF connects patients and caregivers through the CholangioConnect program and monthly virtual patient & caregiver support groups. In addition, the Foundation hosts an annual three-day International conference with attendees and presenters from around the world who represent the major academic institutions, industry, advocacy organizations, patients and caregivers, and regulatory bodies.

CCF provides opportunities for collaboration efforts worldwide through its:

- International Cholangiocarcinoma Research Network (ICRN)
- Scientific and Medical Advisory Board (SMAB)
- Nursing Advisory Board (NAB)
- Industry Council (IC)

These groups work together to improve knowledge about cholangiocarcinoma etiology, prevention, early detection, treatment, and prognosis.

## what is cholangiocarcinoma?

Cholangiocarcinoma, bile duct carcinoma, or bile duct cancer, is a cancerous (malignant) tumor that arises from the tissues in the bile duct and its branches. These cancers may arise at any location along the bile duct and include:

- **Intrahepatic Cholangiocarcinoma:**

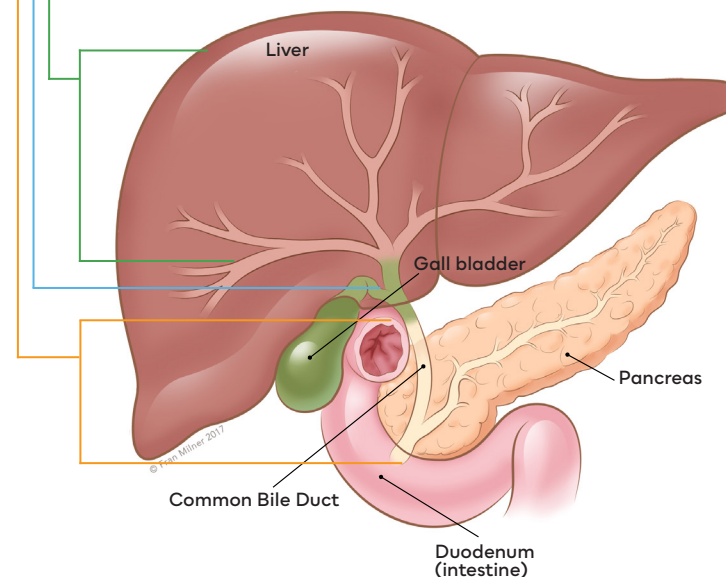
These cancers occur inside the liver, where cancer develops in the hepatic bile ducts or the smaller intrahepatic biliary ducts. They can sometimes be confused with cancers that start in the liver cells.

- **Perihilar (Hilar or Klatskin Tumor):**

These cancers develop where the right and left hepatic ducts have joined and are leaving the liver.

- **Distal Cholangiocarcinoma:**

These cancers occur outside the liver after the right and left hepatic bile ducts have joined to form the common bile duct. This type of cancer is found where the common bile duct passes through the pancreas.



## what are the symptoms?

Cholangiocarcinoma is often labeled a silent disease because often the signs and symptoms go unnoticed until the cancer is in the advanced stages. Symptoms may vary depending on the patient, the size of the tumor, and the location of the tumor. If you are experiencing any of the following, please consult your physician:



Jaundice



Abdominal pain



Itchy skin



Weight loss



Poor appetite



Abnormal liver function test



Changes in stool or urine color



Fever

## what are the risk factors?

Research has shown that some disorders may increase the chances of developing cholangiocarcinoma, including:

- Primary sclerosing cholangitis: chronic inflammation of the bile ducts
- Chronic ulcerative colitis and Crohn's disease: chronic inflammation of the bowel
- Choledochal cysts: sac-like structures forming off the bile ducts
- Liver fluke infection: occurs in some Asian countries when people eat raw or poorly cooked fish
- Liver cirrhosis: damage and scarring of the liver tissue
- Obesity

## what treatments are available?

The course of treatment for cholangiocarcinoma will depend on the location of the tumor(s), and the stage of the cancer, as well as the patient's general health, age, and treatment preferences. Treatments available are evolving and may include chemotherapy, radiation therapy, immunotherapy, targeted therapy, surgical resection, transplantation, clinical trials, and palliative therapy.