Our achievements:

Research

Since 2015, we have invested nearly $2M in research grants to better understand this complex disease and accelerate finding a cure.

Research Fellowship Program

CCF's Research Fellowship Program provides funding for innovative, quality research to early career researchers focused on cholangiocarcinoma.

International Cholangiocarcinoma Patient Registry (ICPR)

This is a secure database of specific and relevant anonymous (de-identified) health information entered by patients and/or their caregivers. Adding your information will assist, accelerate, and support research to improve early detection, diagnosis, advance therapies for prolonging and improving quality of life and lead to a cure.

We have significantly better data when patients complete the survey. Complete surveys at your convenience and in the privacy of your home. Your identified information will remain safe and private, patients' information will never be shared or sold to third parties, unless you give CCF your express permission to do so. There is absolutely no cost for participation. Please visit *cholangiocarcinoma.org/icpr* for more information and to register.

Ciitizen Partnership

We are excited to announce that our partnership with Ciitizen can give you the option to have full access to your health data. Ciitizen gathers your medical records for you and gives you the opportunity to leverage the data by giving others access to it as you deem appropriate. When you control your data, you can more easily coordinate your care, get second opinions and contribute to the ICPR. Please visit *ciitizen.com/ccf* for more information and to register.

Komodo Partnership

We are excited to announce our partnership with Komodo Health Data. CCF uses objective Komodo Health data to power an online specialty map for patients in the United States. This data also allows us to explore the incidence and prevalence of cholangiocarcinoma in the United States, looking at the percentage comorbidities of CCA with other known risk factors, and exploring new disease risk factors.

Mutations Matter Initiative

The Mutations Matter program seeks to educate community physicians and patients about the importance of molecular testing and clinical trial options. For cancer patients, molecular profiling may provide access to effective personalized treatment options.

To learn more about how molecular profiling could lead to better outcomes for patients with cholangiocarcinoma and to spread the word so all cancer patients can receive molecular testing, please visit *mutationsmatter.org* and watch our short videos.

ICRN

CCF launched the International Cholangiocarcinoma Research Network (ICRN), a global collaboration of 100+ physicians and scientists from 65 cancer centers in 17 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 visit *curecc.org/icrn*.

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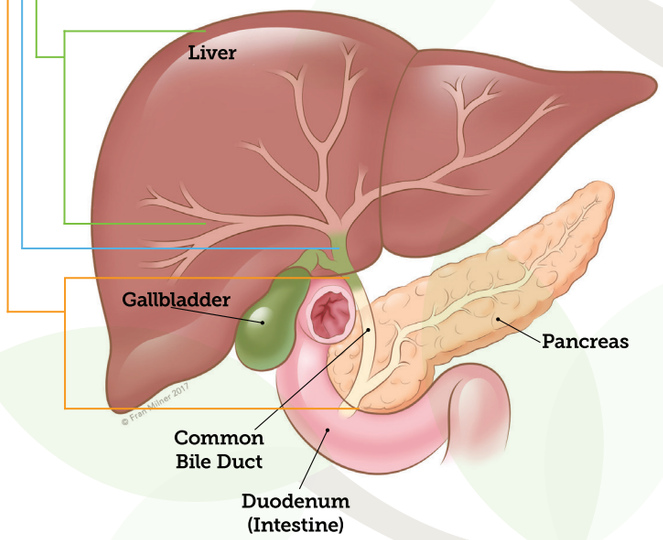
What is cholangiocarcinoma?

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. Only 10% of bile duct cancers are intrahepatic.

Perihilar (Hilar or Klatskin Tumor):
These cancers develop where the right and left hepatic ducts have joined and are leaving the liver. This is the most common type of cholangiocarcinoma accounting for more than half of all bile duct cancers.

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. This subtype accounts for 20 to 30% of bile duct cancers.



What is the biliary system?

The biliary system is comprised of a network of tree-like structure for carrying bile between the liver, gall bladder, and small intestine. Bile is made in the liver and stored in the gallbladder and helps to both break down fats found in foods and rid the body of waste material filtered out of the bloodstream by the liver. Right and left hepatic bile ducts inside the liver collect the bile and join outside the liver to form the common bile duct (extrahepatic bile duct), which carries the bile to the small intestine.

What is extrahepatic cholangiocarcinoma?

Because perihilar and distal bile duct cancers start outside the liver, they are often grouped together and referred to as extrahepatic cholangiocarcinoma.

What are the types of cholangiocarcinoma?

Bile duct cancers can also be divided into types based on how the cancer cells look under the microscope. More than 95% of bile duct cancers are carcinomas and most are adenocarcinomas. Adenocarcinomas are cancers of glandular cells that can develop in several organs of the body. Bile duct adenocarcinomas develop from the mucous glands that line the inside of the duct.

What treatments are available?

The course of treatment for cholangiocarcinoma will depend on the location of the tumor(s), the size 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 surgical resection, liver transplantation, radiation therapy, local therapy, chemotherapy, immunotherapy, targeted therapy, and palliative therapy.

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 scaring of the liver tissue
- Obesity

What are the symptoms?

Cholangiocarcinoma is often labeled a silent disease because many times the signs and symptoms can go unnoticed until the cancer is in the advanced stage. Symptoms may vary depending on the patient, the size of the tumor, and the position of the tumor. Even when there are early signs and symptoms, they may be vague and easily attributed to another disease. Therefore, please consult a physician should any of the following occur:

- Jaundice – yellowing of the skin or eyes
- Abdominal pain
- Itchy skin
- Weight loss
- Poor appetite
- Abnormal liver function
- Changes in stool or urine color
- Fever