



## About Us

### Research

- Since 2006, CCF has funded more than \$1,000,000 for innovative, quality research to find a cure
- CCF values research that nurtures young investigators and promotes collaboration

### International Cholangiocarcinoma Research Network (ICRN)

- A global alliance of research groups working to improve knowledge about prevention, detection and treatment
- Facilitates multi-center basic, translational, and clinical research to open new pathways for diagnosis and drug discovery

### International Cholangiocarcinoma Patient Registry (ICPR)

- The only registry of patient health information related solely to cholangiocarcinoma
- Accelerates research about the incidence and prevalence of cholangiocarcinoma and related disorders

### Book: *100 Questions & Answers about Biliary Cancer*

- Guides patients and their families through diagnosis, treatment, and survivorship
- Available free in both e-copy and print versions at [book.cholangiocarcinoma.org](http://book.cholangiocarcinoma.org)

For more information...

Visit our website:

[www.cholangiocarcinoma.org](http://www.cholangiocarcinoma.org)

Follow us on 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/cholangiocarcinomaorgfoundation](https://youtube.com/c/cholangiocarcinomaorgfoundation)



[vimeo.com/cholangiocarcinoma](https://vimeo.com/cholangiocarcinoma)



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

email:

[info@cholangiocarcinoma.org](mailto:info@cholangiocarcinoma.org)

address:

*Cholangiocarcinoma Foundation  
5526 West 13400 South, #510  
Salt Lake City, Utah 84096  
U.S.A.*

phone:

*(801) 999-0455*

*Our Mission:*  
To find a cure and improve the  
quality of life for those affected  
by cholangiocarcinoma.

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



## What is Cholangiocarcinoma?

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

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. Even when there are early signs and symptoms, they may be vague and easily attributed to another disease.

## What is the biliary system?

The biliary system is comprised of a network or tree-like structure of ducts 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 are the symptoms of Cholangiocarcinoma?

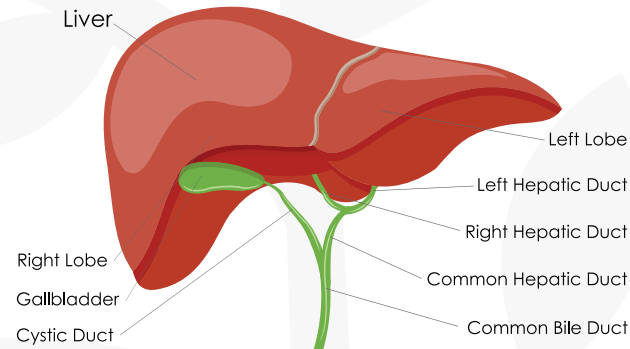
Symptoms indicating cholangiocarcinoma may vary depending on the patient, the size of the tumor, and the position of the tumor. Further, symptoms indicating cholangiocarcinoma may also be symptomatic of other conditions. Therefore, please consult a physician should any of the following occur:

- 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

## What are the risk factors for developing Cholangiocarcinoma?

Research has shown that some disorders may increase the chances of developing cholangiocarcinoma. Disorders leading to increased risk include the following:

- Primary sclerosing cholangitis: chronic inflammation of the bile ducts
- Chronic ulcerative colitis: chronic inflammation of the bowel
- Choledochal cysts: sac-like structures forming off the bile ducts



## What treatments are available for Cholangiocarcinoma?

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 surgery, liver transplant, chemotherapy, radiation therapy, photodynamic therapy, immunotherapy, targeted therapy and palliative therapy.

## What is Intrahepatic Cholangiocarcinoma?

These cancers develop in the smaller bile duct branches inside the liver. They can sometimes be confused with cancers that start in the liver cells. Only 10% of bile duct cancers are intrahepatic.

## What is Perihilar (Hilar) Cholangiocarcinoma?

These cancers develop where the right and left hepatic ducts have joined and are leaving the liver. They are also called Klatskin tumors. These are the most common type of cholangiocarcinoma accounting for more than half of all bile duct cancers.

## What is Distal Cholangiocarcinoma?

These cancers are found further down the bile duct closer to the small intestine. Distal bile duct cancers start outside the liver and make up 20 to 30% of bile duct cancers.

## 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. Cholangiocarcinoma is another name for a bile duct carcinoma.