Cholangiocarcinoma (bile duct cancer) is a cancer of the bile duct of the liver. It starts in the bile duct, a thin tube, about 4 to 5 inches long, that reaches from the liver to the small intestine. The major function of the bile duct is to move a fluid called bile from the liver and gallbladder to the small intestine, where it helps digest the fats in food.

Cholangiocarcinoma is a rare cancer. Of the top eight deadliest cancers, seven are rare. Rare cancers have a 5-year survival rate under 50% with the cholangiocarcinoma 5-year survival rate being approximately 20%.

There are three types of cholangiocarcinoma: intrahepatic, perihilar, and distal, and the mortality rate has increased dramatically in the last decade. According to a recent study, it is estimated that by 2040, liver and bile duct cancer will be the third deadliest cancer in the United States.

An estimated 10,000 people in the United States develop cholangiocarcinoma each year, and almost 2 out of 3 people with cholangiocarcinoma are 65 or older when it is found. The chances of survival for patients with bile duct cancer depends to a large extent on its location and how advanced it is when it is discovered.

Patients are typically diagnosed at a late stage due to no validated early method of detection. Symptoms of jaundice, abdominal pain, itchy skin, and weight loss are symptoms that do not usually present till advanced disease progression.

The Cholangiocarcinoma Foundation was founded in 2006, in Salt Lake City, Utah, by a family who lost a loved one to cholangiocarcinoma.

The SOI(c)3 has grown to become the leading global resource in research, education, and patient advocacy. Its goal is to find a cure and improve the quality of life of those impacted by cholangiocarcinoma.