



FOR IMMEDIATE RELEASE

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New cancer program launched by Cholangiocarcinoma Foundation to connect patients, caregivers with essential resources

*Newly Diagnosed/New to CCF program gives cholangiocarcinoma patients and caregivers
information, resources and support to navigate cancer diagnosis*

SALT LAKE CITY, UT – The Cholangiocarcinoma Foundation (CCF) is proud to announce the launch of its [Newly Diagnosed/New to CCF](#) program to support patients and caregivers following a cholangiocarcinoma (bile duct cancer) diagnosis. There are approximately 40,000 cases of cholangiocarcinoma (CCA) diagnosed around the world each year.

Although it is considered a rare cancer, the incidence of CCA is growing. A recent study ([JAMA Network Open](#)) estimates that by 2040, liver and bile duct cancer will be the third deadliest cancer in the United States. That is why CCF's goal is to connect with each person diagnosed with cholangiocarcinoma. The program is the key to achieving that objective by providing critical information to patients including CCA specialists, second opinions, biomarker testing, support and additional resources.

The need to connect with CCA patients is important. For example, six out of six patients from a recent advisory board meeting said they received no information when they were diagnosed by their physicians. Some patients didn't even know what kind of CCA they were diagnosed with.

This program provides essential information and vital resources for newly diagnosed patients through their entire cancer journey including treatment options. Physicians can now refer their patients to CCF for the support their patients need outside of the exam room.

"At the time of diagnosis, I was given a short period of time and at first given little hope," said long-term survivor, Christy Landon. "I have seen so many people working hard for the cause of cholangiocarcinoma and their progress and enthusiasm for their work brings hope. It's encouraging to me to know that by engaging in the Foundation's programs, I can be a part of that hope."



The program works through a series of emails and a webpage with helpful information, resources and support that includes a Specialist Map and guidance to getting a second opinion. Patients and caregivers can learn how to advocate for their own care and what to do to discover clinical trials that are matched to best treat their cancer. Patients also receive a free care kit full of creature comforts that support them through treatment, such as chemotherapy and immunotherapy.

Patients and their caregivers may get involved with this program by visiting the [Newly Diagnosed/New to CCF](#) webpage. There, they will be greeted with a welcome video from Melinda Bachini, CCF's Advocacy Director and 12-year survivor of CCA. They can also find other CCA survivor stories and step-by-step instructions of what they should do as soon as they are diagnosed.

"I am committed to helping newly diagnosed patients get the resources they need to navigate a cholangiocarcinoma diagnosis and become empowered to advocate for the care they need," said CCF Director of Advocacy Melinda Bachini.

The program was made possible by the following sponsors:

- Zymeworks,
- Incyte,
- QED Therapeutics,
- Servier,
- Taiho Oncology.

PHOTOS & VIDEO ARE AVAILABLE HERE:

<https://www.dropbox.com/s/bjc4yumcg8t6hwm/official%20CCF%20logo.jpg?dl=0>

About cholangiocarcinoma:

Cholangiocarcinoma, pronounced (koh-LAN-jee-oh-KAR-sih-NOH-muh), is a highly lethal and rare bile duct cancer of the liver with a poor prognosis. With approximately 10,000 cases a year being diagnosed in the United States, cholangiocarcinoma is the second most common primary liver cancer in the world. It is often diagnosed at advanced stages when treatment is only minimally effective, emphasizing the imminent need for novel therapies.

About the Cholangiocarcinoma Foundation (CCF):

Founded in 2006, the Cholangiocarcinoma Foundation is a global 501(c) (3) non-profit organization. Its mission is to find a cure and improve the quality of life for those affected by bile duct cancer. CCF supports basic & translational research and raises awareness in the cholangiocarcinoma community through advocacy, education, collaboration, and research. For more information, please visit our website at cholangiocarcinoma.org.

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