



**FOR IMMEDIATE RELEASE**

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**Rare Cancer Day is supported by Cholangiocarcinoma Foundation  
with video series called 'Patient Voices'**

*Foundation offers free care kits to newly diagnosed cholangiocarcinoma  
patients and caregivers residing in the US*

**SALT LAKE CITY, UTAH** - Any cancer diagnosis is frightening but when it is rare cancer with few treatment options, the diagnosis can be especially devastating. To increase awareness of cholangiocarcinoma, lethal bile duct cancer, the Cholangiocarcinoma Foundation (CCF) is supporting the annual awareness day - Rare Cancer Day.

"Cholangiocarcinoma is a deadly cancer of the bile ducts. Because the symptoms from this cancer can initially be mild and are common to many other diseases, it is important that we educate the public," said Foundation CEO and Founder Stacie Lindsey. "We want to assist patients to get to the right doctor, have the right diagnostic tests and understand all of their treatment options. We can then give them the support and resources they need to advocate for their care."

Rare Cancer Day is devoted to raising awareness about rare cancers, the need for greater research funding, early diagnoses and patient support. Spearheaded by the NORD Rare Cancer Coalition™, which is composed of 27 rare cancer-specific member

organizations, including CCF, Rare Cancer Day is observed on September 30 to highlight the challenges patients face and to unify individuals living with rare cancers.

In support of its core value of putting patients first, the Foundation is commemorating Rare Cancer Day by featuring a series of videos on [YouTube](#) called, "[Patient Voices.](#)" Each video depicts cholangiocarcinoma survivors who share their backgrounds and experiences from being diagnosed with rare bile duct cancer to connecting with the Foundation. These videos are less than five minutes each and advocate hope while raising awareness about cholangiocarcinoma, which is diagnosed in an estimated 10,000 Americans annually.

Because rare cancers have a 5-year survival rate under 50% with the cholangiocarcinoma 5-year survival rate being approximately 20%, connecting with every patient diagnosed is a goal of the Foundation. Anyone newly diagnosed with cholangiocarcinoma in the US may receive a free care kit full of creature comforts selected by patients they found useful as they received treatment, such as chemotherapy and immunotherapy.

The care kit is a small token from the Foundation's [Newly Diagnosed/New to CCF](#) program. The free program works through a series of emails and a webpage with content that includes:

- Specialist Map, so patients can find cholangiocarcinoma specialists in their area,
- How to get a second opinion, which includes a virtual consultation,
- Patient registry to be connected to treatment options through clinical trials,
- Information about biomarker testing and its benefits,
- Free eBook, "100 Questions & Answers About Cholangiocarcinoma, Gallbladder and Bile Duct Cancers" by Dr. Ghassan Abou-Alfa & Dr. Eileen M. O'Reilly.
- Event calendar, discussion board, mentoring program and more.

"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. "Rare Cancer Day gives us the opportunity to not only raise awareness about cholangiocarcinoma but to connect to patients who need the support we can provide."

The Foundation is also [accepting donations](#) from anyone impacted by rare cancer. Donations made on Rare Cancer Day are earmarked specifically to continue the advocacy and outreach the newly diagnosed program is designed to offer worldwide.

**PHOTOS & VIDEO ARE AVAILABLE HERE:**

<https://www.dropbox.com/sh/xjnmyaxzdpznze4/AAC2GZrOcZKfX1MbSCB5TCiGa?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](http://cholangiocarcinoma.org). Video: <https://www.youtube.com/watch?v=A3QsNX-1td0>

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