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Salt Lake City, Utah

The Cholangiocarcinoma Foundation and Patient Crossroads Partner to Launch Global Patient Registry in June 2014

Patients, Researchers, Industry and Leading Medical Experts Join Forces to Accelerate Cholangiocarcinoma Research

The Cholangiocarcinoma Foundation (CCF) announced the upcoming launch of the International Cholangiocarcinoma Patient Registry (ICPR), the first ever patient registry for people with cholangiocarcinoma (bile duct cancer).

The ICPR is a patient-centered database designed to collect relevant clinical and scientific information about people with cholangiocarcinoma. Patients, caregivers, and family members will record and update personal disease characteristics in a private, secure online profile. Entries will capture stage, treatments, test results, side effects, and treatment responses. All data will be made available in de-identified form, giving doctors, researchers, and patients themselves an unprecedented resource to determine the best approaches to care, according to each patient's unique clinical history.

According to Donna Mayer, CCF Executive Director, "A central database of de-identified data that is shared among researchers worldwide is a crucial step in helping investigators to understand bile duct cancer and allow them to identify patients to participate in clinical trials and research surveys. This, in turn, will increase our understanding of this disease and will ultimately lead us to better treatments and a cure."

Empowering Patients

Patients will be encouraged to be active contributors in the mission to find a cure for Cholangiocarcinoma. By opting-in, patients will participate in their own healthcare by supplying researchers with the most up-to-date data possible. The more data the registry collects, the more efficiently researchers will be able to focus their endeavors.

"For a small investment of time, patients can provide a wealth of knowledge to researchers" says Stacie Lindsey, CCF President and Founder. "The ICPR will empower patients and families to improve their own health outcomes and help make a difference that can be felt around the world."

Partnering to Accelerate Research

The Cholangiocarcinoma Foundation has partnered with Patient Crossroads to create this innovative tool to speed progress towards a greater understanding of cholangiocarcinoma and lead to improved therapeutic options and ultimately a cure. The ICPR has been reviewed and approved by the Chesapeake IRB, an independent ethics committee responsible for protecting the rights and welfare of people involved in research.

About The Cholangiocarcinoma Foundation

The Cholangiocarcinoma Foundation (CCF) is a global non-profit organization committed to seeking a cause and cure for cholangiocarcinoma (bile duct cancer) through research, education, collaboration, and advocacy. More information is available at www.cholangiocarcinoma.org.

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