



RESEARCH ADVOCATE PANEL

2027 Sponsorship Prospectus

About the Cholangiocarcinoma Foundation

The Cholangiocarcinoma Foundation's (CCF) mission is to find a cure and improve the quality of life for those affected by cholangiocarcinoma (CCA). Founded in 2006 in Salt Lake City, Utah, by a family who lost a loved one to the disease, CCF has grown into a global leader in patient support, education, advocacy, and funding basic, clinical, and translational research. CCF's core values are patients first, collaboration, innovation, and urgency.

About our Research Advocate Panel

The Cholangiocarcinoma Foundation's Research Advocate Panel provides pharmaceutical and biotechnology companies with meaningful, non-binding insights from individuals with lived experience in CCA, including patients, survivors, and caregivers.

This panel is designed to help companies better understand how research, clinical trial design, education, communication, and outreach are experienced by real patients and caregivers. By integrating the patient and caregiver voice early and meaningfully, companies can gain practical recommendations that may improve the relevance, feasibility, clarity, and impact of their research and engagement strategies.

Participants are selected from CCF's trained Research Advocate program and include individuals who have personal experience with CCA and demonstrated engagement in the CCA community. These advocates bring informed, real-world perspectives that can help bridge the gap between scientific innovation and the lived experience of patients and families.

The Research Advocate Panel is intended to serve as a strategic patient-engagement opportunity, helping industry partners better understand patient priorities, barriers to participation, quality-of-life concerns, trust factors, and communication needs from diagnosis through treatment.

What Companies Can Learn

A Research Advocate Panel can help companies better understand the practical and emotional realities that influence how patients and caregivers experience research, trials, education, and care.

Key areas of insight may include:

- Clinical trial design and feasibility
- Barriers to clinical trial awareness, enrollment, participation, and retention
- Patient and caregiver perspectives on trial burden, including travel, testing, visit schedules, eligibility criteria, and financial or logistical challenges
- Patient-prioritized outcomes, including quality of life, symptom management, daily functioning, caregiver impact, and treatment decision-making
- Concerns related to earlier diagnosis, biomarker testing, treatment sequencing, access to specialists, and care navigation
- Clarity and accessibility of educational materials, consent language, trial summaries, and patient-facing communications
- Trust factors that influence how patients and caregivers evaluate research opportunities, industry communications, and clinical trial information
- Practical recommendations that may improve protocol feasibility, patient education, outreach, and overall relevance to the CCA community

For more information, contact:

Kaylin Allenbrand, Director of Corporate Partnerships, kaylin.allenbrand@curecca.org

Meeting Format

CCF's Research Advocate Panel is a virtual engagement designed to provide structured feedback on materials, concepts, or questions companies are exploring.

The typical process includes:

Project Planning & Goal Alignment

Together, we align on objectives, review materials, define focus areas, and identify desired feedback.

Advocate Recruitment

CCF recruits at least six trained Research Advocates whose expertise aligns with the project's goals.

Independent Advocate Review

Advocates independently review company materials and provide thoughtful, detailed feedback.

Feedback Collection & Synthesis

CCF collects, organizes, and synthesizes advocate feedback into clear themes, actionable insights, and practical recommendations to help inform next steps.

Optional Follow-Up Discussion

An optional follow-up meeting with CCF staff provides an opportunity to review findings, clarify key themes, answer questions, and discuss potential next steps.

Timeline

Planning and execution typically take 3–4 weeks after the pledge is received, depending on the depth and complexity of the project.

Investment

The total investment for a virtual Research Advocate Panel is **\$15,000**. This includes full facilitation and coordination by CCF.