

Research Advocate Panel

2025/2026 PROSPECTUS

Overview

The Cholangiocarcinoma Foundation (CCF) Research Advocate Panel enables companies to gain valuable, non-binding insights from individuals with lived experience in cholangiocarcinoma (CCA), including patients and caregivers. This panel is designed to help companies enhance the design, relevance, and impact of their research, education, and outreach efforts by integrating the patient and caregiver voice early and meaningfully in the process.

Participants are selected from CCF's trained Research Advocate program and include individuals who have personal experience as CCA patients, survivors, or caregivers and have demonstrated a strong interest and engagement in the CCA community.

Companies may utilize a Research Advocate Panel to:

- **Ensure Research Relevance:** Gain feedback from individuals with lived experience to help shape research questions, study designs, and outcomes that matter most to patients and caregivers.
- Enhance Trial Design and Accessibility: Understand potential barriers to enrollment and retention from the patient perspective, leading to more inclusive and patient-friendly protocols.
- Inform Communication and Education Strategies: Test messaging, educational content, or outreach materials to ensure clarity, relevance, and resonance with target audiences.
- **Demonstrate Patient-Centered Commitment:** Showcase a transparent and collaborative approach to R&D by actively involving patients, caregivers, and advocates in the research development process.
- **Bridge Science and Community Insight:** Receive informed, real-world input that helps translate scientific innovation into practical impact for patients living with cholangiocarcinoma.

Format

CCF's Research Advocate Panel is a virtual engagement designed to provide feedback on materials or concepts that companies are exploring. The typical process includes:

- CCF and the company agree on goals, review materials, and define focus areas.
- CCF identifies and recruits a panel of 6 research advocates aligned with the company's needs.
- Advocates review Materials independently, followed by the collection and synthesis of feedback.
- (Optional) A follow-up meeting between the company and CCF staff may be scheduled to discuss results.

Timeline: The whole process typically takes 3–4 weeks after the pledge is received, depending on the depth and complexity of the project.

Company Benefits

By conducting a Research Advocate Panel, your company will receive:

Full-Service Management

CCF handles all aspects of the panel, including:

- Participant recruitment and communication
- Confidentiality agreements
- Agenda and material creation
- Feedback collection and synthesis
- Optional post-review surveys and follow-up call

Non-Binding Patient-Centered Feedback

- Honest input directly from advocates with lived experience
- Informs protocol development, educational strategies, or communication language

Increased Relevance & Impact

• Helps ensure company materials and strategies resonate with the CCA community

Visibility & Collaboration

- Demonstrates commitment to patient engagement
- Strengthens industry-community trust and transparency

Investment

The total investment for a virtual Research Advocate Panel is **\$15,000**, which includes full facilitation and coordination by the Cholangiocarcinoma Foundation, participant honoraria, preparation of meeting materials, and a post-event feedback report. An optional follow-up meeting with CCF staff is also included to discuss insights further and the next steps.

CCF's obligation is fulfilled by delivering on the commitments articulated in this prospectus for the year indicated above, as well as by the value the sponsor receives from its association with CCF's intellectual capital, partners, and constituents.