

Cholangiocarcinoma Foundation Policy on Industry Engagement

Revised 1.31.2022

Policy Scope

This policy focuses on mission-related companies that serve the interests of the cholangiocarcinoma community -- those companies within the medical products industry (“Industry”), including those that develop drugs, biologics, diagnostics, data, and devices aimed at providing better therapeutic options and improved quality of life for cholangiocarcinoma patients.

This policy shall govern related activities at all levels and by all who represent the Cholangiocarcinoma Foundation (CCF), including board members, staff, and volunteers.

Background and Purpose

CCF’s mission is to support patients and render CCA a treatable disease. As the largest, professionally led, non-profit organization serving cholangiocarcinoma patients and their loved ones worldwide, CCF delivers a comprehensive menu of personalized and essential services at no charge.

To ensure that such programs and services are available to those in need, CCF often partners with industry on the design, development, and/or implementation of special events, programs, research studies, and educational initiatives. CCF seeks industry partners who share its commitment to cholangiocarcinoma patients and their families. By partnering with industry, CCF seeks to enhance its ability to meet its mission and strategic objectives. Engagement by CCF with industry partners will be at the sole direction of CCF leadership, in compliance with the tenets of this policy. The overall values of the organization will guide this engagement.

To avoid conflicts of interest or the appearance thereof, CCF has developed the following policy to guide and clearly define such organizational relationships.

Collaboration Evaluation Criteria

Using its sole discretion, CCF will evaluate and execute potential industry collaborations according to a set of criteria reflecting its overall mission, values, and priorities and its focus on the needs of the cholangiocarcinoma community.

These criteria include:

- Ability to clearly define the collaboration’s consistency with and contribution to advancing CCF’s mission
- Clear understanding among all parties (and ability to communicate broadly with external audiences) about how CCF will retain its independence & control within the collaboration
- Complete compliance with CCF conflict of interest policies as defined in this policy (see below)
- Maintenance of overall categorical income balance from various sectors and sources within CCF revenues.

- Execution of an explicit, detailed, written agreement among the parties
- Compliance with well-defined operating procedures within CCF for review, approval, and ongoing evaluation of each collaboration (as well as preservation of the organization's ability to terminate any collaboration)
- Complete transparency about the terms and activities of each collaboration

Program Independence and Control

CCF will explore collaboration opportunities with industry partners across all programs, including outreach, education, and awareness efforts; research and clinical development programs; advocacy and public policy initiatives; and events. CCF retains complete independence to evaluate the content and direct control over any collaborative activities conducted/presented under the CCF name or logo, specifically:

- CCF maintains total independence and has ultimate authority over program design, development, content, speaker selection, and/or policy positions
- CCF does not endorse any medical product, treatment protocol, or medical service, nor does it provide treatment advice to patients
- CCF does not link from its website to any product-specific websites
- Every effort will be made to ensure that all programs and information presented in written or online materials will be presented in a fair and balanced manner
- Corporate partners wishing to use the CCF name, insignia, or logo in public relations, marketing, or promotional materials or activities must first seek prior written approval by CCF
- CCF will not, under any circumstances, accept contributions from corporations that are contingent upon any public policy position and/or public policy activity; CCF maintains total independence and ultimate authority over its policy-making activities without regard to any corporate partnership
- CCF reserves the right to sever any corporate partnership with, and return contributions from, any entity that participates in public policy activities that CCF finds offensive or that are in significant conflict with CCF's policies or positions
- CCF reserves the right to approve the participation of third parties that its corporate partners may recommend for involvement in any program, project, or event
- CCF does not enter into exclusive partnerships with corporate entities
- CCF does not sell or otherwise provide its mailing list to any corporate partners
- Materials, programs, and data developed, created, or collected by CCF are the sole property of CCF; they must carry the CCF copyright or trademark, and as such, cannot be changed, modified, or duplicated without prior written permission from CCF

Conflict of Interest

CCF will evaluate all potential engagements with industry to determine their consistency with CCF's Conflict of Interest policy, including the following:

- CCF will assess, seek to avoid, and responsibly manage all conflicts and appearance of conflicts in all potential engagements
- CCF will not endorse or promote any specific therapy or service for patients
- CCF will not engage with companies whose policies, practices, or actions conflict with the organization's mission

- Any significant industry engagement (including participation in events, acceptance of donations, or collaborative activities) undertaken by individuals on behalf of CCF in support of CCF's mission will be:
 - Evaluated according to well-defined operating procedures
 - Clearly documented
 - Transparent
 - Fully consistent with existing CCF Conflict of Interest policies
- CCF will conduct due diligence to prevent situations of actual or perceived financial or other personal benefits to any CCF employees, trustees, and officers stemming from any industry collaboration
- CCF will maintain safeguards and transparent policies to ensure that funding support from industry for CCF programs does not influence the accuracy, scientific credibility, and objectivity of information provided to the public or any constituency by the organization
- In the event any such activity ultimately fails to meet these requirements, the activity will be terminated immediately by CCF

Income Balance and Fundraising Guidelines

In pursuit of its mission, CCF generates financial and in-kind support from a broad range of supporters, including individuals, foundations, and companies. CCF will strive to maintain balance among various categories of supporters and within those categories.

In developing collaborations with industry partners focused on specific program areas, CCF may offer well-defined benefits – such as public recognition, input on joint projects, attendance at CCF events, etc. -- in consideration of financial support and sponsorships. As a general practice, CCF will work to develop productive relationships with industry partners that move beyond transactional exchanges and focus on working collaboratively on programs and initiatives that advance the mission of CCF.

Operating Procedures

CCF will review and prioritize requests for engagement with industry partners based on alignment with its mission and the potential for any engagement to advance its strategic objectives.

CCF may offer benefits to certain industry partners based on their engagement as members in an Industry Council or other CCF effort.

All significant potential industry relationships will be assessed by CCF leadership and formalized through written agreements in line with this policy. They will clearly state the scope of the collaboration, its governance, and any financial terms. Such agreements will be reviewed and signed by a member of the CCF leadership not directly involved in negotiating the agreement and will include provisions for regular evaluation and review.

CCF's Board of Directors reserves the right to amend this policy at will and without prior notice. The granting of financial support to CCF signifies agreement with all terms of this policy.