
Camp/Industry Collaboration Discussion Guide

Revised - January 2017

Collaborating With Industry; Policy Discussion Guide

This guide was created to help camps discuss the possibility of collaborating with industry, and develop appropriate policies should camps decide to collaborate.

Camps need resources to operate; for bleeding disorders camps one place to find resources is through collaboration with industry. Collaboration with industry raises serious existential and ethical questions in the bleeding disorders community. Rather than encouraging blanket decisions for or against anything, our goal is for each camp to have a thoughtful discussion of the issues, and make independent decisions based on the values of the community the camp serves.

The guide works by identifying key collaboration related issues and offering different considerations on each. Camps which choose to collaborate need a clear policies guiding their relationship with industry. Policies which recognize the different interests involved, promote transparency, and establish ethical practices are essential to building trust in the camp among campers, staff, and the community.

The guide was created by the CIWG (Camp Industry Working Group) of the NACCHO (North American Camp Conference of Hemophilia Organizations) conference. The CIWG is tasked with promoting responsible practices related to industry collaboration. The NACCHO conference is dedicated to “fostering excellence and innovation in camp programs for people with bleeding disorders”.

Members of the CIWG are recruited from different organizations and companies which serve the bleeding disorders community to ensure a wide range of perspectives form our work. The CIWG does not oppose or endorse any position on collaboration; our goal is to provide a tool which helps camps undertake their own independent discussions and decisions on the issues.

This guide does not constitute legal guidance. For information on relevant state and federal laws you should seek guidance from a knowledgeable professional.

The participation of any individual on the CIWG is not an endorsement of this guide or any position on industry collaboration by their employer/camp/organization.

Creation/dissemination of this guide does not constitute an endorsement of the guide or any position on industry collaboration by NACCHO organizers the Arizona Hemophilia Association, or conference sponsors, Pfizer and Biogen.

See Page 10 for CIWG members and Transparency information.

Questions/comments on the guide & collaboration issues can be sent to:
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I. Funding

Funding is generally defined as the payment of money in the form of grants, donations, or sponsorships. It can be difficult for adult campers, staff, families, and clinicians to have an informed opinion on industry funding as they often aren't informed about camp finances.

PROS

- Can provide significant funds camp isn't otherwise able to raise.
- May reduce time needed to fundraise from other sources, allowing effort to be spent on other camp and chapter activities.
- Could be a more secure source of funding than public fundraisers.
- Might offer companies a way to invest in the success of the community they serve.

CONS

- Can subject the camp to extra reporting and utilization requirements.
- May obligate camp to recognize companies in ways that make it appear the camp endorses certain products.
- Could make the camp dependent on industry money for support.
- Might bias the camp/community relationship to the company and industry.

Who to get input from?

Adult campers, families, staff, clinicians serving the campers, and companies serving your community.

Questions to ask?

- Do you really need the money to run a successful camp?
- Will taking funds for camp reduce funds offered for other community needs?
- How will this change the relationship of the camp/chapter with industry?
- What recognition and community access do companies expect in return for their support?
- Does accepting industry money compromise community independence in dealings with industry?

II. Give-away items

Having branded "giveaway" items at camp is a form of collaboration because community members, other companies, and people outside of camp generally perceive the distribution of items with company logos as evidence of a relationship.

PROS

- Can be a source of needed items for campers that won't cost you money.
- May be a source of gifts or prizes for campers at no expense to camp.

CONS

- Can make it look like camp is endorsing a certain product or company.
- May make it look like company helps camp even if they don't give anything else.

Who to get input from?

Adult campers, families, and companies serving your community.

Questions to ask?

- Will you accept items from only some or all of the companies who offer them?
- Is the item genuinely useful to campers, or just nice to have?
- Does the item contain product or other information?

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III. Sponsored field trips

A field trip is an activity at a venue off grounds directly paid for by industry, and which may or may not have a direct educational value.

PROS

- Can give campers chance for experiences they might not otherwise have at camp.
- May provide supplemental resources for the camp program budget.
- Could make camp more appealing, especially to certain age groups.

CONS

- Can confuse who has liability for issues that may happen during the trip.
- May give campers an image of the company not related to their products/services.
- Could create unrealistic or misleading camper and staff expectations for camp.

Who to get input from?

Adult campers, staff, and clinicians serving the campers.

Questions to ask?

- How does the activity/program fit with the goals and values of camp?
- What does the company expect to receive for sponsoring the trip?
- Does the company expect employees not screened/accepted as camp staff can go on the trip?

IV. Industry provided camp activities & programs.

Some companies offer activities and programs where they provide the materials and/or facilitators (company employees or contractors) to run them. Some of these programs are educational, recreational, or combine the two in some form.

PROS

- Can be a source of useful activities to augment camp planning efforts.
- May be a source of activities camp might not otherwise be able to offer.
- Could offer industry a way to participate in camp if industry aren't allowed as staff.

CONS

- Can limit you from judging the content or value of such programs beforehand.
- May include branding or people not covered by camp screening/conduct policies.
- Could make liability for problems during such activities and programs unclear.

Who to get input from?

Adult campers, staff, clinicians serving the campers, companies serving your community.

Questions to ask?

- How does the activity/program fit with the goals and values of camp?
- Is there branding on the activity materials and/or leaders
- How will company employees/contractors working with campers be screened and supervised?

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V. Industry Employees At Camp

Allowing industry employees to be part of camp is one of the most debated forms of collaboration in our community. Today, greater industry focus on community engagement and the constant pressure to find enough staff make this a critical issue to address.

Who is “Industry” ?

- **Sales/Marketing Representatives** - Individuals (including patients and clinicians) paid directly by a manufacturer/home care company or as a contractor (whether full time, part-time, or per diem) and who discuss or promote companies, treatment products or treatment product delivery services for the purposes of influencing patient-consumer choices.
- **Non-sales Representatives** - Individuals (including patients and clinicians) paid directly by a manufacturer/home care company or as a contractor (whether full time or part-time) for a function which expressly does not involve talking about product or service choices.
- **Consultants** - Any individual paid by manufacturers, homecare, or contractors per diem or per event for non-sales/marketing roles (speakers, activity leaders, advisors, etc.).

NOTE: Being classified as a Sales/Marketing Representative, Non-sales Representative, or Consultant does not change if the person participates in/at camp on their own/unpaid time or paid leave time.

Potential Roles In/At Camp For Industry

- Camp Board Member or Planning Team Member
- Camp Staff/Director or Camp Medical Staff/Medical Director
- Guest Activity/Program Leader
- Session Guest Presenter/Speaker/Panelist and Exhibitors

Where to Start:

It's important to begin your discussion by dealing with two key underlying questions.

“Can you trust industry?”

Patient-consumers and industry have different interests which affect how they act, or are perceived to act. These interests may coincide, diverge, or conflict depending on the situation.

At camp, “trusting” industry means being able to rely on them to act within boundaries established in the best interests of campers, staff, and families. It's possible a person's employment may “conflict” with their ability to fully respect boundaries on their conduct in/at camp. Acknowledging this is part of selecting and supervising those involved with camp. Can you set and enforce boundaries? Do these boundaries affect the willingness and ability of industry to participate in camp? Performing your “due diligence” is the only way to get the answers you need.

“Are they industry if they come on their own?”

Interacting with industry can affect patient-consumer attitudes and choices of products/services, which in turn can directly affect patient health. Formal (speaking with a rep at a display) and casual (sharing a campfire) interactions can have equal impact. Moreover, casual interactions may involve minors, or take place in settings which can't be well monitored for inappropriate behavior (discussing medical information, patients asking for or being offered inducements).

Being on their own unpaid time or company paid time doesn't change who a person works for, their potential to impact patient-consumer choices, or the potential for conflicts of interest. If you allow those who work for industry to participate in/at camp then transparency and appropriate policies are essential to the integrity of your camp program.

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Where Does This Leave Us?

Pros

Industry employees can be talented, hardworking members of your camp team and useful speakers/exhibitors at camp. It can be fairly argued that industry employees are held to higher standards of conduct by and because of their employer. Inviting industry employees to be in/at camp can benefit camp by forging close ties to those with other desired resources.

Cons

Industry employees might only participate in/at camp because it's part of their job and their involvement grants them access to patient-consumers. It can be fairly argued allowing industry at camp blurs the patient and business relationships outside camp. Having industry in/at camp may create an unhealthy dependency on a particular company, or industry in general.

A Sample Policy Outline

- 1) Identify what the policy is meant to achieve. Sample Goals:
 - a) Protect patient privacy.
 - b) Ensure disclosure of any connection to industry and potential conflicts of interest.
 - c) Prevent unwelcome and/or improper marketing.
- 2) Specify which roles sales, non-sales, and consultants may or may not fill in/at camp. *NOTE: Because industry speakers and exhibitors attend camp expressly in an industry capacity there should be a separate policy for them; your chapter may already have such a policy.*
- 3) Specify behavior which conflicts or appear to conflict with policy goals to establish clear boundaries of what is/not acceptable behavior. EXAMPLE - At camp, camp/medical staff are **NOT ALLOWED** to:
 - a) Wear or have clothing/items with logos or other branding.
 - b) Distribute items with logos or other branding.
 - c) Convey information about individuals to their employer.
 - d) Arrange at camp to have contact with campers/families after camp.
 - e) Have contact with minor campers after camp unless a parent/guardian is present.
 - f) Discuss product information, and current or potential choices of products/services with anyone *unless authorized in advance as part of planned educational activities.*
 - g) Ask/answer specific questions about medical treatment/treatment options *unless the questions are directly related to your assigned role at camp (e.g. - medical staff, presenter, etc.).*
 - h) Discuss personal medical information with or about someone *unless directly related to providing medical care for the person during camp.*
- 4) Designate someone (i.e. camp director) responsible for handling policy violations-and implementing the consequences for the violation, e.g. - a written warning, dismissal from participation in camp, notification of the person's employer.
- 5) Create a document explaining the industry policy; require industry participants read and sign the document. *NOTE: All camps should have a code of conduct for all staff members to sign.*
- 6) Prior to camp, inform all: staff, campers/families and community members that you have an Industry Camp Participation Policy. Ideally this would be provided to everyone or at least upon request. In addition, it is recommended to have the policy at camp for reference.

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VI. Proactively Engaging With Industry

It can be helpful to engage industry in a conversation about their company's policy on self-governance, especially if you offer year-round programming. Self-governance refers to established standards of employee professional conduct when interacting with the community. It is important to note these standards are not imposed on them by the community or government regulators but the company. Some questions you can ask to better understand how industry governs themselves are:

Do they have a Policy for how they engage Patients/Consumers?

- Do they approach patients/consumers proactively to provide information to them or is their engagement limited to answering specific questions in a reactive manner?
- Do they have guidelines on what they can discuss with patients/consumers?
- Does their company require them to identify themselves as an industry representative prior to engaging a patient/consumer?
- Does the company have a policy in place that restricts them from giving medical advice?

Do they have a Privacy Protection Policy?

- Does their company have a policy regarding the collection of consumer names?
- Does the policy require the patients/consumers to "opt in" to receive information from them?
- What policies does the company have in place to guard personal information?
- Does the company have a policy in place that addresses patient privacy?

Does the company have a Volunteer Policy?

- Does the policy allow for participation in activities related to the employee's primary job?
- Would the employee volunteer for this program/organization if they were not employed within this therapeutic area?
- Could volunteering for this organization result in the perception of a conflict of interest or could involvement be used as a means for commercial gain?

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VII. Establish Accountability And A Working Policy

Camps expend community resources for community benefit; this obligates camps to demonstrate how they adhere to clear and responsible standards of operations.

1) DISCLOSURE

Individuals and companies should provide camp with requested information relating to their involvement. Camps, in turn, should only request relevant information and use it for specified camp purposes.

- What do you need to know about a person to judge their suitability for involvement in/at camp – employer, certifications, experience, criminal background, residence, references, etc.?
- What do you need to know about a contractor – who's paying for what, is there branding, who's liable for what, how are non-camp program individuals screened and supervised, etc.

2) TRANSPARENCY (Communicating Policies):

Once policies are finalized, be sure to communicate them to appropriate stakeholders, such as industry members, camp/chapter leadership, parents of campers, volunteers, etc. Some points to consider when communicating your policy:

- Be clear, concise and consistent in communicating the policy; the aim is transparency.
- Outline pertinent information for stakeholders and where more information can be obtained.
- Consider including an overview of the policy in the relevant camp materials that parents receive.
- Parents should know what (if any) access industry representatives may have to their campers at camp as well as the extents and limitations of that access.
- Indicate specific people or groups where any questions or concerns stakeholders may have regarding the policy may be directed to.
- As appropriate, describe the steps that would be taken if a violation of the policy were to occur.
- Be sure to continuously communicate the policy as new stakeholders become involved in camp.

3) CONFLICT OF INTEREST:

When conflict exists can be debatable. In a community where people often “wear many hats” it's difficult to create a workable policy preventing the appearance all conflict. Therefore the goal should be to:

- Recognize where the potential for conflict and harm exist.
- Set rules for dealing with campers and camper information.
- Require full disclosure of “multiple hat” and other potential conflict situations.
- Let campers, staff, families, and industry know you have conflict of interest rules.
- Regularly re-examine what you consider to be a conflict of interest because organizations grow, people change roles, and the forms of industry collaboration evolve.

4) RECIPROCITY WITH INDUSTRY

If your camp collaborates with industry, it's important to know what the policies of each company are, and share your policies with industry to promote transparency.

- What are the requirements for requesting and using funds?
- What's expected in return for support; e.g. - recognition, reporting, patient access, etc.
- Who is liable for what during sponsored activities/programs?
- Are industry members applying as staff on company time, paid vacation time, or unpaid time?
- Who at the company handles problems regarding their policies and employees?
- How will camp protect industry employees against inappropriate behavior by campers/staff – e.g. asking about products/services at camp, wanting special favors in return for the patient's business, maligning an industry member from a company they don't like, etc..

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CIWG Disclosure & Transparency Statement

- a) The content of this guide was determined by majority vote of the CIWG members; it was reviewed and accepted by the NACCHO Chair and Planning Committee before distribution.
- b) Members of the CIWG are experienced camp/medical staff, industry employees, and other members of the community in order to provide a range of perspectives on the issues.
- c) As conference sponsors, Pfizer and Biogen were invited to participate in the creation of the guide for their insights into the issues.
- d) As an already established ethics body, the NHF Ethics Working Group was invited to provide advisors who could furnish ethical insights into the issues; the EWG and NHF have no role in the CIWG.
- e) This guide will be distributed to all bleeding disorders camps in the U.S. The CIWG is available for consultation and feedback on future revisions to this guide.

2017 CIWG Members and Advisors

- **Bob Graham** - a person with a bleeding disorder, Director of the BDAN Family Camp in New York, NYSBDC Public Policy Coordinator, member of the NACCHO Planning Committee, and CIWG Chair.
- **Donald Douglas** - a Customer Relations Specialist with Accredo Health, NACCHO Planning Committee member, and longtime volunteer with many camp, family and youth programs.
- **J.D. Kohutka** - Senior Regional Business Director for Pfizer Hemophilia in the East Region, with 20 years industry experience specializing in biopharmaceutical/specialty sales and marketing.
- **Jim Munn**- Program/Nurse Coordinator, University of Michigan Hemophilia and Coagulation Disorders Program, member of the NHF Ethics Working Group, Camp Nurse for Eagle Expedition, and lead nurse Camp Bold Eagle (2nd session) of Michigan.
- **Luke Phfeifer** - Deputy Director of the Bleeding Disorder Foundation of Washington, and the Camp Director for Camp I-Vy and Camp I-Vy Jr. in Washington state.
- **Roz Witte** - Regional Sales Director for Pfizer Pharmaceuticals, with 19 years of experience in the Hemophilia market place and originally involved with NACCHO program evaluation/support.
- **Dr. Kristie Ostash** - *Advisor* - a pediatrician and mother of a patient, member of the NHF Board of Directors, member of NHF/MASAC, and co-chair of the NHF Ethics Working Group.
- **Bill Berger**- *Advisor* - a Social Worker/Program Coordinator, Washington University (St. Louis, MO) Center for Treatment of Bleeding and Blood Clotting Disorders, member of the NHF Social Work/Ethics Working Groups and former Board member of the Gateway Hemophilia Association.

DISCLAIMERS

- 1) Participation by an individual on the CIWG does not constitute an endorsement of the guide or any position on industry collaboration by their employer/camp/organization.
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