



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

Standards for Industry and Industry Agents

Definitions: **Industry** refers to any corporation that provides goods and services to the Colorado Chapter's bleeding disorders community on a for-profit basis. These corporations may include, *but are not limited to*, **specialty pharmacy, home care, and pharmaceutical** companies.

A NHF Colorado Chapter **Event** may include, but is not limited to, a meeting, educational program, camp, outing, social gathering, retreat, or fund-raising activity.

An Industry **Agent** is a person who is employed by or otherwise compensated by Industry either on a full-time, part-time or contract basis. An Industry **Representative** is an Industry Agent who is representing Industry at a NHF Colorado Chapter Event. Any individual who attends a NHF Colorado Chapter Event and wears an Industry name tag or item of Industry logo apparel will be assumed to be an Industry Representative.

An **Exhibit** is a table or other mechanism for displaying Industry marketing materials at an Event. Exhibits may be restricted to designated areas and time frames.

Consumers are persons who have a bleeding disorder and their family members who may, at some point in time, use the goods and/or services provided by Industry. In the context of a NHF Colorado Chapter Event this includes accompanying friends and family in attendance.

The National Hemophilia Foundation – Colorado Chapter welcomes everyone in its efforts to support the community of persons affected by bleeding disorders. NHF Colorado Chapter is a non-profit organization; we do not endorse any pharmaceutical product, specialty pharmacy, or home care service. We recognize that our membership includes many who are employed by or otherwise associated with Industry. We are also aware that Industry employs some persons who are themselves affected by a bleeding disorder and who are a direct part of the community supported by the NHF Colorado Chapter.

The NHF Colorado Chapter makes every effort to ensure that the members of the bleeding disorders community are always able to make a clear distinction between its own activities and those of Industry. Further, it is essential that we create beneficial and pressure-free experiences for our community members at NHF Colorado Chapter events and programs. Accordingly, the NHF Colorado Chapter has developed the following standards.

Use of NHF Colorado Chapter Materials in Industry Publications

The use of NHF Colorado Chapter materials – including but not limited to the NHF Colorado Chapter logo, articles from its newsletter(s), brochures, event fliers, and its website – are expressly prohibited without advance written approval (electronic mail and faxes are acceptable) from the NHF Colorado Chapter Executive Director.

Industry Representatives at NHF Colorado Chapter-hosted Events

1. **All** Industry Representatives must identify themselves as such prior to the start (*i.e.*: at sign-in or registration) of an Event, and by wearing name tags or apparel with their company name or logo **at all times** during the Event.
2. Only NHF Colorado Chapter-approved Industry Representatives of duly registered Event sponsors may distribute marketing materials or any other materials during the Event, such distribution will be limited to agreed upon materials and area.
3. Industry Agents may not attend a NHF Colorado Chapter Event (excluding fundraisers) unless their company is one of the sponsors and/or NHF Colorado Chapter has granted permission. In addition, NHF Colorado Chapter can limit participation of those in a dual role (Industry Agent/Consumer) who does not live within the NHF Colorado Chapter catchment/designated coverage area.
4. Industry Representatives may not conduct raffles, sweepstakes or similar activities where names are required for entry (regardless of whether participants may enter without charge) at NHF Colorado Chapter Events.
5. The only allowable method for collecting names and addresses of consumers is by using a NHF Colorado Chapter-approved signup form, which clearly states that the consumer is voluntarily giving their contact information with the understanding that the company may follow up by phone or by mail. No other method of collecting contact information from Event participants will be permitted.
6. No Industry Representative may distribute any type of medication to consumers; this includes over-the-counter medications such as anti-inflammatory drugs and antacids. External-use products such as wraps, cold/hot packs, and hand sanitizers are permitted.
7. No organization may conduct any official meeting, presentation or other activity during the Event without express approval of NHF Colorado Chapter Executive Director.
8. NHF Colorado Chapter retains the right to reject any proposed presentation that is contrary to the goals of NHF Colorado Chapter.
9. Industry Representatives may attend general education sessions only, not small group sessions such as breakouts or support groups, without express approval of NHF Colorado Chapter Executive Director.
10. NHF Colorado Chapter will not be responsible for transporting, storing, shipping, setting up or displaying any materials for Industry use at Events.
11. No photos or videos may be taken during any Event without consent of the participant and prior consent of NHF Colorado Chapter Executive Director.
12. Industry Representatives must agree to abide by any additional standards set forth by NHF Colorado Chapter that may pertain to specific Events.
13. NHF Colorado Chapter will maintain all RSVP lists. Industry Representatives may not add or invite participants without NHF Colorado Chapter Executive Director consent.
14. NHF Colorado Chapter will set limits on the number of Industry Representatives allowed at each event, depending on level of sponsorship. These expectations will be clearly communicated prior to each Event.

Additional Standards for Industry Agents Who Are Also Consumers

These rules apply regardless of whether the consumer individual is a member of the NHF Colorado Chapter bleeding disorders community:

15. An Industry Agent who is also a Consumer must specify prior to the start (*i.e.*: at sign-in or registration) of the Event whether he or she is attending as an Industry Representative or as a Consumer. In other words, “*when you walk in the event door, you are either a Consumer or*

an Industry Representative, and you retain that status for the duration of the Event.”

If attending as a Consumer you:

- a) Will not use any information obtained as a result of your attendance or participation for any other purpose other than attendance or participation in such events/programs
- b) Must not conduct **any marketing activity** for the duration of the Event (marketing activity includes but is not limited to wearing company apparel, handing out business cards, giving out logo items, etc.)
- c) Will not solicit name or addresses of attendees, and must ensure that all attendees' personal information acquired during the Event is kept in confidence and will not be used for any Industry-related marketing, sales, or financial gain of any kind

Confidentiality Standards

16. All Industry Agents and Representatives must abide by the NHF Colorado Chapter Confidentiality Standards to ensure that event participants feel comfortable sharing personal information.

- a. All information shared by participants during NHF Colorado Chapter events is to be maintained confidential.
- b. The only individuals to have full names of program attendees will include NHF Colorado Chapter Event representatives (which may include NHF Colorado Chapter staff, board members, assigned volunteers and/or HTC staff).
- c. NHF Colorado Chapter will not release participants' full names and/or confirm individual registrants to event sponsors, industry agents or representatives without the express written consent of the individual.

Any **exemption** from or **waiver** of these standards must be approved on an individual and case-by-case basis in advance by the NHF Colorado Chapter Executive Director.

Violation of these standards may result in penalties to the individual in violation or to his or her entire Industry organization. Penalties may include additional restrictions, the assessment of additional fees, or forfeiture of the privilege of attending future programs with NHF Colorado Chapter.