

Standards for Industry and Industry Representatives/Agents

Definitions: **Industry** refers to any to companies that manufacture factor or profit from the sale of factor and/or additional medical treatments used by members of the bleeding disorders community. These corporations may include, *but are not limited to*, **specialty pharmacy, home care, and pharmaceutical** companies.

A **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 an event. Any individual who attends a 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 chapter event this includes accompanying friends and family in attendance.

Hemophilia of South Carolina (HSC), welcomes everyone in its efforts to support the community of persons affected by bleeding disorders. HSC is a non-profit organization; we do not endorse any pharmaceutical product, specialty pharmacy, or home care service. We recognize that individuals we serve include 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 chapter.

HSC 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 chapter events and programs. Accordingly, HSC has developed the following standards.

Use of Hemophilia of South Carolina Materials in Industry Publications

The use of HSC materials – including but not limited to the its 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 HSC's Chapter executive director.

Industry Representatives at HSC's - 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 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 chapter event unless their company is one of the sponsors and/or the chapter has granted permission. In addition, the HSC reserves the right to limit participation of those in a dual role (Industry Agent/Consumer) who do not live within the 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 HSC Events.
5. The only allowable method for collecting names and addresses of consumers is by using a HSC Chapter-approved sign-up 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 methods 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 company or Industry Representative may conduct any official meeting, presentation or other activity during the Event without express approval of the Chapter. This includes off-site meetings, meals, etc.

8. The Chapter retains the right to reject any proposed presentation that is contrary to the goals of the Chapter or the Chapter's event.

9. Industry Representatives may attend general education sessions only, not small group sessions such as breakouts or support groups, without express approval of the Chapter.

10. The 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, the chapter executive director, and prior consent of the Chapter.

12. Industry Representatives **must** agree to abide by any additional standards set forth by Hemophilia of South Carolina that may pertain to specific events or programs.

13. The Chapter will maintain all RSVP lists. Industry Representatives may not add or invite participants without written consent and approval.

Additional Standards for Industry Agents Who Are Also Consumers

These rules apply regardless of whether the consumer individual is a member of the Hemophilia of South Carolina chapter bleeding disorders community:

14. 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

15. All Industry Agents and Representatives must abide by HSC's Chapter Confidentiality Standards to ensure that event participants feel comfortable sharing personal information.

a) All information shared by participants during chapter events is to be maintained confidential.

b) The only individuals to have full names of program attendees will include chapter event representatives (which may include staff, board members, committee members and/or HTC staff).

c) The 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 Chapter executive director.

Violation of these standards may result in penalties to the individual in violation or to his or her entire Industry company. Penalties may include additional restrictions, the assessment of additional fees, or forfeiture of the privilege of attending future programs of Hemophilia of South Carolina. -----Updated 8.2018