



*Hemophilia Foundation  
of Maryland*

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*Proudly Serving the Maryland Bleeding Disorder Community* 

### **Hemophilia Foundation of Maryland (HFM) Standards for Industry Representatives January 2016**

**Definitions:** **Industry** refers to any company and/or corporation that provides goods and services to the HFM bleeding disorders community on a for-profit basis. These corporations may include, but are not limited to, specialty pharmacy, homecare, and pharmaceutical companies.

**An HFM 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 Hemophilia Foundation of Maryland event. Any individual who attends a Hemophilia Foundation of Maryland event and wears an Industry nametag or item of Industry apparel will be assumed to be an Industry Representative.

An **Exhibit** is a table or booth used 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 an HFM event, this includes accompanying friends and family members in attendance.

HFM welcomes everyone in its effort to support the bleeding disorders community and values the education its Industry Partners provides the community. HFM is a non-profit organization; so, we do not endorse any pharmaceutical product, specialty pharmacy, or homecare service. The policies in this document are congruent with HFM's operational philosophy to create an equal opportunity for all companies to provide educational information to the consumers in the bleeding disorders community. It is also HFM's intent to avoid circumstances where unfavorable conclusions could be made in terms of the HFM's relationship to industry. Consequently, HFM will at all times maintain a neutral position in terms of pharmaceutical, specialty pharmacy, and/or homecare companies.

Further, 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 HFM.

HFM makes every effort to ensure that the members of the Maryland bleeding disorders community are always able to make a clear distinction between their own activities and those of Industry. Further, it is essential that we create beneficial and pressure-free experiences for our community members at HFM events and Programs. Accordingly, The HFM Board of Directors has developed the following guidelines beginning January 2016.

### **Use of Hemophilia Foundation of Maryland Materials in Industry Publications**

The use of HFM materials, including, but not limited to, the HFM logo, articles from the HFM newsletter, brochures, event fliers, and its website, are expressly prohibited without advance approval (written or electronic) from the HFM Staff and/or Executive Board of Directors.

### **Industry Representatives at Hemophilia Foundation of Maryland-hosted events**

1. All Industry Representatives must identify themselves as such prior to the start (i.e. at sign-in or registration) of any HFM event, and by wearing name tags or apparel with their company's name or logo at all times during the event. A list must be given to HFM staff of all company's representatives attending an HFM event.
2. Only HFM-approved Industry Representatives of registered event sponsors may distribute marketing materials or any other materials during an HFM event. Such distribution will be limited to agreed upon materials and area. Sponsors are welcome to share their contact information with participants, but may not have sign-in sheets, which are strictly prohibited by HFM.
3. Industry Agents may not attend an HFM event unless their company is one of the sponsors of the event. In addition, HFM may limit participation of those in a dual role (Industry Agent and Consumer) who do not live within the HFM coverage areas.
4. Only two industry agents from each company may attend an HFM event, unless express email or written communication stating otherwise is received from HFM.
5. 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 any HFM events.
6. Solicitation of children under the age of 18 is strictly prohibited.
7. Industry Agents and/or Representatives **may not** use sign-up sheets to obtain consumer contact information at any HFM events.
8. No Industry Representative may distribute any type of medical advice or 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.

9. No Industry Representative may conduct any official meeting, presentation, or other activity during an HFM event without express approval of HFM staff.
10. HFM retains the right to reject any proposed presentation that is contrary to the goals of The Hemophilia Foundation of Maryland.
11. Industry Representatives may attend general sessions only, not small group sessions such as breakouts or support groups, without the express approval of HFM staff.
12. HFM will not be responsible for transporting, storing, shipping, setting up, or displaying any materials for Industry use at events.
13. No photos or videos may be taken during any event without the consent of the participant and prior consent of The HFM.
14. Industry Representatives must agree to abide by any additional standards set forth by HFM that may pertain to specific events.
15. HFM staff will maintain all RSVP lists. Industry Representatives may not add or invite other participants without HFM consent and advance approval.
16. Educational topics should be the motivation for consumers to attend HFM events.

### **Industry Representatives at Industry/HFM-hosted events**

#### Pharmaceutical Company Hosted Events –

17. All Industry hosted events in the HFM service area must be hosted in partnership with HFM. \*HFM will cease it's working relationship with any Industry Representative/Company that plans an event without with the express permission and partnership of HFM – **no exceptions**.
18. The agenda, materials, and presentation must be approved by HFM and follow guidelines outlined in the introduction of this document.
19. Invitations for all Pharmaceutical Company hosted events are disseminated by HFM, and all RSVPs come to the chapter office, or HTC involved in the event.
20. Consumers will not be pressured to change product or be given medical advice at any HFM event.
21. HFM will acknowledge all companies sponsorship at the event.

### **Additional Standards for Pharmaceutical Company Agents:**

21. **Direct patient marketing outside of HFM events is strictly prohibited.** HFM makes an effort to host numerous educational and exhibition events throughout the year to allow Pharmaceutical Companies to market their company and product in a safe and controlled environment. However, recently HFM members have indicated they are receiving invitations to private dinners with pharmaceutical companies and are then pressured to try that company's product, i.e., direct marketing outside of HFM events. HFM strongly discourages such behavior and encourages all patients to first discuss available and preferred treatment options with their medical providers and HTC staff.

## **Additional Standards for Industry Agents Who Are Also Consumers**

The aforementioned rules apply regardless of whether the consumer individual is a member of the Hemophilia Foundation of Maryland bleeding disorders community or another chapter.

22. 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 through the 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 names 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.

If an Industry Agent is found doing any of the above, they will be asked to leave the session, and may be prohibited from attending events in the future.

## **Confidentiality Standards**

23. All Industry Agents and Representatives must abide by the Hemophilia Foundation of Maryland Confidentiality Standards to ensure that event participants feel comfortable sharing personal information.
  - a) All information shared by participants during Hemophilia Foundation of Maryland events is to be maintained confidential.
  - b) The only individuals to have full names of program attendees will include Hemophilia Foundation of Maryland event representatives (which may HFM Staff and HTC Staff).
  - c) Hemophilia Foundation of Maryland 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 form or waiver of these standards must be approved on an individual and case-by-case basis in advance by The HFM.

**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 HFM.**

The HFM truly values the commitment of our Industry Partners to the bleeding disorders community, and we look forward to partnering with all of you in the future.

Signed this \_\_\_\_\_ day of \_\_\_\_\_, 2016, the below named individual understands and agrees to abide by the above standards.

\_\_\_\_\_  
Industry Company Name

\_\_\_\_\_  
Industry Representative Signature