

Program Registration Guidelines

Definitions

“Constituent”– Shall include persons with an inherited bleeding disorder or members of their immediate family/household member.

“Inherited Bleeding Disorder”– Bleeding disorders are a group of inherited conditions in which there is a problem with the body’s blood clotting process. They are characterized by extended bleeding after injury, surgery, trauma or menstruation. Bleeding can also begin on its own. Specific inherited bleeding disorders can include: hemophilia A (factor VIII deficiency), hemophilia B (factor IX deficiency), von Willebrand disease (VWD), platelet disorders, and rare factor deficiencies including I, II, V, VII, X, XI, XII, XIII.

“Coverage Area” – The territorial jurisdiction of VHF as outlined by VHF’s Articles of Incorporation includes the residents of the cities and counties of the Commonwealth of Virginia, other than the cities of Alexandria, Fairfax, Falls Church, Herndon, Manassas, Manassas Park and Vienna and the counties of Arlington, Fairfax, Fauquier, Loudon, Prince William and Stafford.

- **Constituents location of treatment** - Individuals who live outside of VHF’s territorial jurisdiction but receive their primary bleeding disorder treatment within VHF’s territorial jurisdiction would also be considered part of VHF’s coverage area.

“No-Show” - One that confirms a space via email, does not attend, and does not cancel their reservation prior to the event.

“Late Cancellation”– One that confirms a space via email and then cancels after confirmation and/or identified deadline for cancellation.

The Virginia Hemophilia Foundation (VHF) strives to provide quality educational programs to “constituents” living in the VHF “coverage area”. The purpose of these guidelines is to ensure that VHF can continue to deliver educational programs for all constituents.

RSVP Management Guidelines

VHF reserves the right to determine one’s place on a roster by:

- Constituent standing and event registration history.
- Coverage area, if outside of coverage area, then:
 - Constituents location of primary bleeding disorder treatment (i.e. Hemophilia Treatment Center (HTC), hematologist, etc. is in Virginia)
- Late cancellation, excessive cancellation, and/or no-show history
- Dual role – an industry representative who is also a constituent (see **Standards for Industry, Associated Organizations, and their Agents Guidelines** for details)
- Attendance and participation at additional educational events over the past year
- Target audience of event (families, adults, teens, etc.)
- Number of RSVPs vs. capacity of the event
- Date/time of registration (if event is first come, first served)



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Event Registration Guidelines

- **Event Registration and Confirmation** - VHF requires that all attendees RSVP online and then reply to the confirmation email prior to an event.
- **Out of Coverage Area Registration Guidelines** - Constituents that live outside of VHF's coverage area and are interested in attending a program may participate if:
 - Space is available, which includes ensuring that no constituents who are part of VHF's coverage area will be turned away.
 - The per person (or per family) fee is paid prior to attending the event. The fee will vary per program, please email info@vahemophilia.org for more information.
- **Change in Number of Attendees** – Please inform VHF when you modify your RSVP numbers after you have confirmed registration for an event. This enables staff to purchase an accurate amount of food, beverages, and event tickets.
- **Registration Cancellation** – VHF requires all persons who have confirmed a space at an event to provide as much notice as possible when they are not able to attend. Some events may have a specific late cancellation deadline (i.e. events with an overnight hotel stay, events with admission tickets, summer camp, etc.)
- **Event No-Show Guidelines** – VHF will require a \$25 fully-refundable deposit to accompany any future reservation if a member has “no-showed” for 2 events in a 12-month period. Once a member has had less than 2 “no-shows” in a 12-month period, the deposit will be waived.
- **Late Cancellations, Excessive Cancellations, or No-Shows** – Cancellations or no-shows for VHF events for any reason other than illness and/or family emergencies will be documented and you will receive an email from VHF stating as such. VHF understands that emergencies and extenuating circumstances arise and reserves the right to evaluate on a case-by-case basis.

Hotel Assistance Guidelines

Virginia Hemophilia Foundation (VHF) may provide one hotel room for VHF constituents* (age 21+) that live within the coverage area* for select educational programs (e.g. annual education meeting, advocacy training). Some additional restrictions may apply such as constituents must live more than 30+ miles away from the event location.

Hotel No-Show Guidelines - VHF will require members to use their credit card number to reserve hotel rooms at overnight programs and events if they have “no-showed” to an event within the last two years where a hotel room was being held in their name. After the two-year period this requirement will be waived.



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Some constituent families may be larger than what a typical hotel room can accommodate, and two hotel rooms may be needed for those families. Families that need more than one hotel room and are unable to financially afford the cost can apply for hotel financial assistance. Applications must be received at least two weeks prior to the event RSVP deadline.

Hotel Financial Assistance Guidelines:

- Assistance is given to VHF constituents that live within the coverage area.
- Assistance is given to constituents in good standing and prior history of late cancellations, excessive cancellations and/or no-show history will be taken into consideration (see Program Registration Guidelines).
- Assistance is given to families that can attend the entire educational meeting.
- Assistance will be determined through a review process conducted by volunteers on the Financial Assistance Program Committee. Demographic information will be removed prior to being sent to the Committee for review.
- Assistance is limited to funding and hotel room availability.

Camp Youngblood Guidelines

VHF contracts with Camp Holiday Trails (CHT) to offer Camp Youngblood, a summer camping experience for children aged 7-17.

VHF reserves the right to determine one's place on the Camp Youngblood roster by:

- Constituent standing and event registration history.
- Coverage area, if outside of coverage area, then:
 - Constituents' location of primary bleeding disorder treatment (i.e., Hemophilia Treatment Center (HTC), hematologist, etc. is within VHF/HACA coverage area.)
- Late cancellation, excessive cancellation, and/or no-show history.
- Attendance and participation at additional educational events over the past year (not applicable to new families.)
- Number of applications vs. capacity of the event.

Camp Youngblood "No-Show" Guidelines:

- VHF is financially responsible for all campers within their coverage area who have a confirmed spot at Camp Youngblood (a confirmed spot requires that you meet all CHT application deadlines).
- If a confirmed camper is a "no-show" to camp, parents/caregivers may be responsible for reimbursing VHF and/or HACA the full camp amount (cost per child is \$700) and/or paying CHT to reserve your spot for the following year.