

# VHF STRATEGIC PLAN SURVEY - THEMES AND TRENDS REPORT

## VHF STRATEGIC PLAN SURVEY

SURVEY DATE	NUMBER OF RESPONSES & DIAGNOSES	SURVEY COLLECTION
10/15/2023 to 10/30/2023	<b>42:</b> 28 hemophilia A, 8 hemophilia B, 4 vwd, 2 hemophilia C	Via Google Forms - link distributed at Medical Symposium (largest and most well attended event of the year) and by email

## PURPOSE OF SURVEY

To collect direct feedback from the VHF bleeding disorders community (consisting of persons with a Bleeding Disorder (BD), their immediate family members, and those who identify as a person with a BD AND a caregiver) to help steer the direction of our Strategic Planning Process. In many cases, modern treatments have changed what it means to live with a bleeding disorder, also the COVID-19 pandemic has changed our lives in many ways. With this in mind, we asked questions about the future relevance of the chapter and the education and social needs of the constituents we serve over the next 2 – 5 years.

## MAIN THEMES

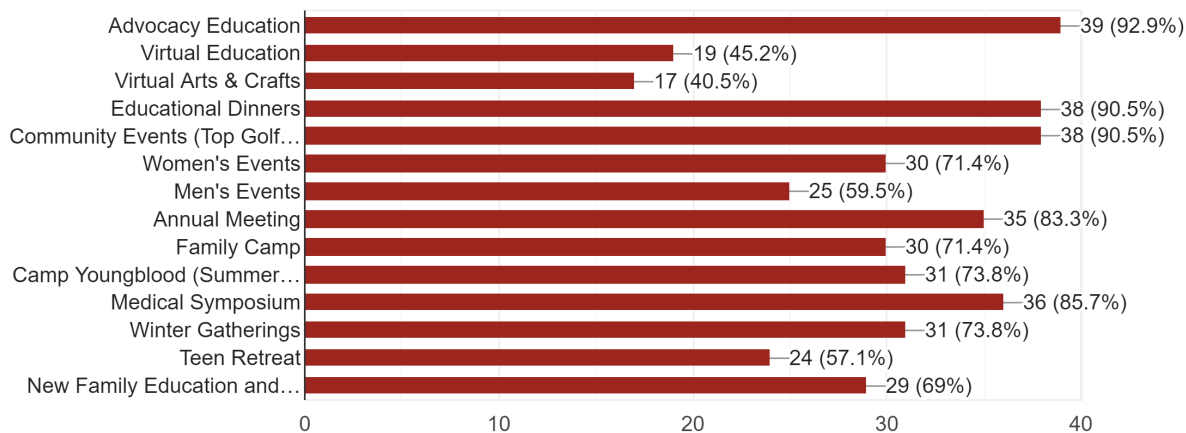
- **Gratitude** VHF is currently relevant to the respondents of this survey and gratitude for the work of the chapter was expressed numerous times. The community still wants to gather and have time to connect in-person.
- **Treatment Advancement** There have been major advancements in treatment for the bleeding disorders community, especially hemophilia A, and with that the biggest change was how much easier day-to-day life had become.
- **Persons With A BD - Overall Needs Have Not Changed** For most of the respondents the need for varied education, social interaction, and bleeding disorder support has not changed, especially for those directly affected with a BD.
- **Caregivers - Day-to-Day Looks Different** Survey responses were mostly from family members and caregivers (hemophilia A), who report that they have seen the biggest change in their day-to-day lives with the switch to Hemlibra and their need for education and support are less than what they needed in the past (this was not true for those directly affected by hemophilia A who reported the same level of need if not more.)
- **Hemophilia B - Needs Are still Significant** This was not true for family members, caregivers, and those directly affected with hemophilia B – most of those respondents report that their long-acting factor is not as effective as they would like and are having break through joint bleeds, pain and the need for more support transitioning their kids from port to peripheral veins.
- **Future Needs - Help Keeping Up With Changing Treatment** Across the board the future needs over the next 2 – 5 years were for continued education on keeping up with the ever-changing treatment landscape and new therapies – especially gene therapy
- **Unmet Needs – Help understanding The Transition From Childhood to Adulthood** Caregivers need help knowing how to support their kids with transition from childhood to adulthood (this was a big trend, and it appears to be more for caregivers than the kids themselves) this looks like transitioning from one center to another and transitioning to independence in life choices
- **Unmet Needs - Women** Advocating for women's access to care and more opportunities for education across the reproductive lifespan of women (adolescents, family planning, childbirth, medical procedures, and menopause) was also a big trend.

## PROGRAM TRENDS

- **Time spent together as a community is still very important** with an emphasis on unstructured time so that natural connections can still happen, keeping in mind to reintroduce community members since there has been a gap in time spent together.
- **Keeping in-person events is a priority** of most of the community.
- **Virtual Events unpopular** - percentage of people wanting to continue virtual events was the lowest and wanting to discontinue was the highest.
- **Top 3 events** – 1. Advocacy Education 2. Educational Dinners & Community Events and 3. Medical Symposium
- No one chose Men’s Programming, Teen Programming, or Medical Symposium as programs to discontinue.
- **New program ideas** official welcome packet for new families & meet and greet time, college & career information in addition to kid to teen/teen to adult transition education, young adult programming, women’s programs with education for the entire community (not just women), infusion training still being asked for, aging issues, reproductive/family planning education.
- **The need for programming and social time just for children** was also emphasized.

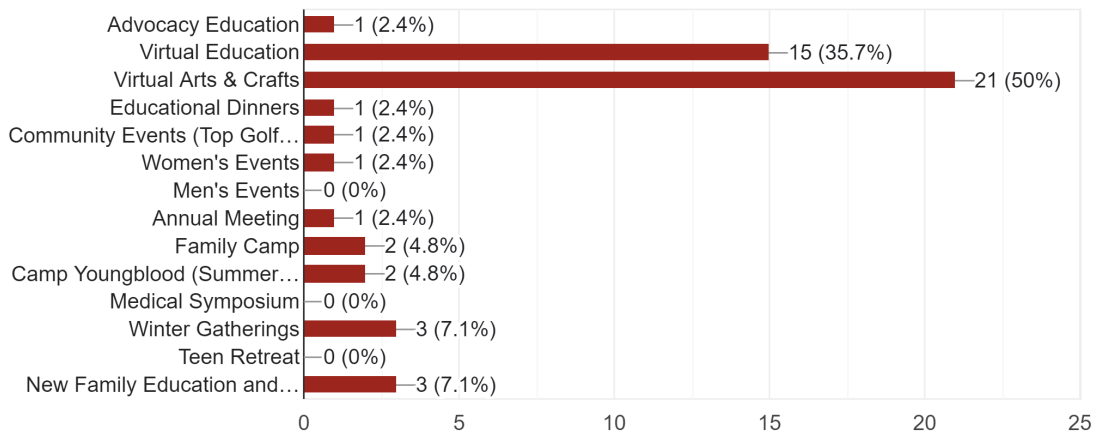
Check all of the following events/programs that you think VHF should continue to offer:

42 responses



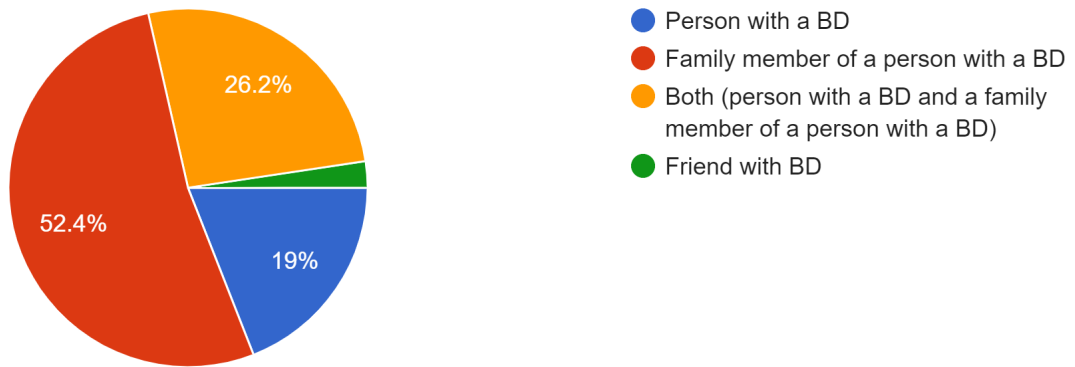
Check all of the following events/programs that you think VHF should DISCONTINUE:

42 responses



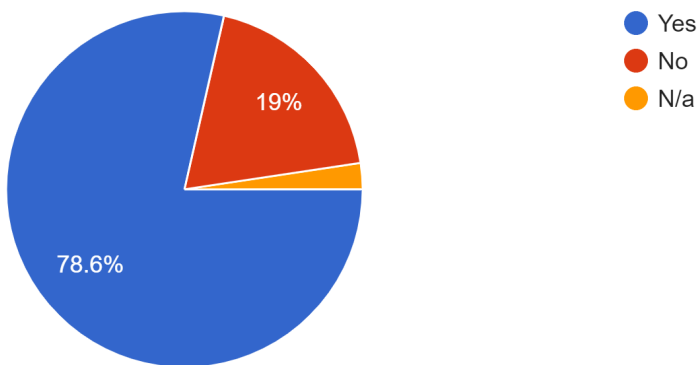
### What is your affiliation with the Bleeding Disorders (BD) Community?

42 responses



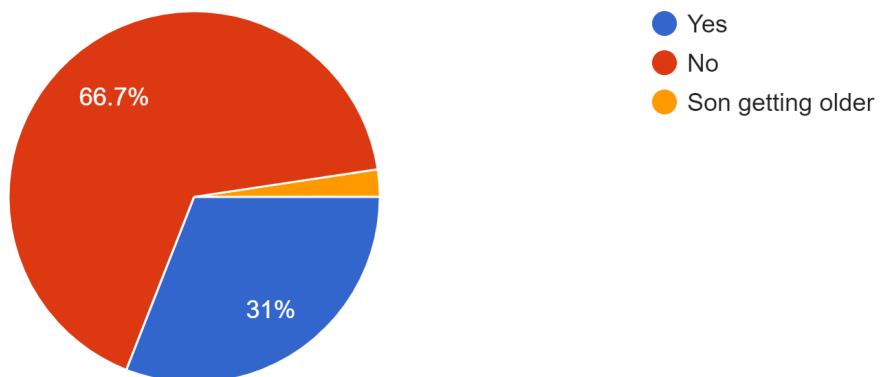
### Have there been advancements in treatment for your (or your family member's) bleeding disorder?

42 responses



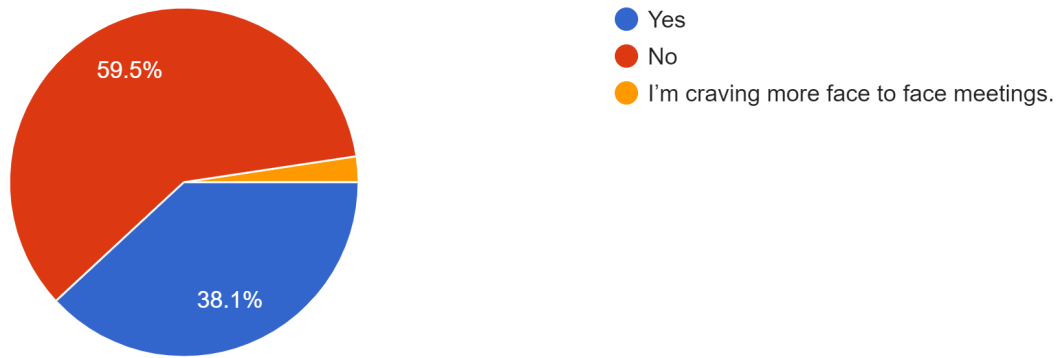
### Has your bleeding disorder related educational needs changed?

42 responses



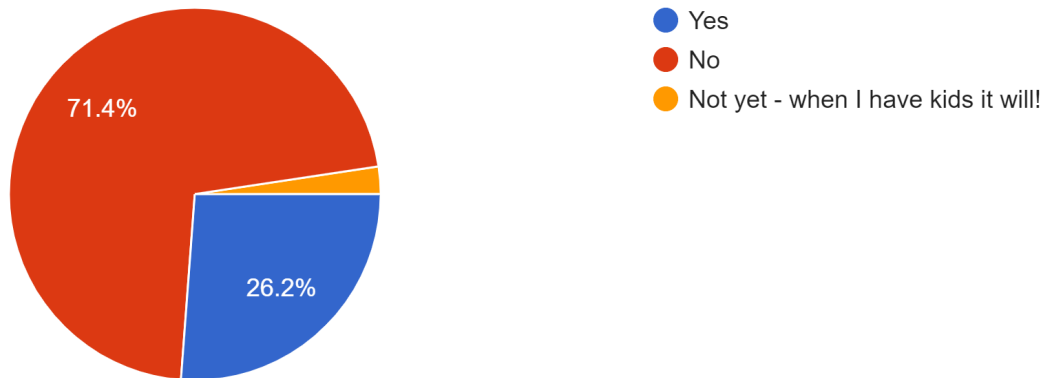
### Has your need or desires for social interactions within the bleeding disorders community changed?

42 responses



### Has your need for bleeding disorder support changed?

42 responses



### Have new/emerging treatments altered the impact of bleeding disorders in your life?

42 responses

