

Collection of Patient Self Reported Experiences at National Severe Von Willebrand Disease (VWD) Conference

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Introduction

VWD Connect Foundation's National Type 3/Severe Von Willebrand Disease Conference has been held annually for three years. The Conferences had both full assembly general sessions and smaller group breakout sessions. An Audience Response System (ARS) was used during the general sessions to give attendees a voice and allow data to be gathered about the physical and emotional needs of the attendees and their caregivers. Patients were queried concerning symptoms, treatments, quality of life and available support. Each year approximately 70 patients participated representing over 35 states with ages from infancy to 70's. The data was immediately available to patients, caregivers and medical providers on Faculty at the conference.

Methods

An anonymously numbered handheld clicker was distributed to patient attendees or adult caregiver responding for a patient under 18 years of age. The multiple-choice questions first established demographics (age, gender, diagnosis, and Hemophilia Treatment Center (HTC) care) to allow data collected to be filtered by demographics. The remaining questions addressed medical and psychosocial topics including bleeding/family history and medical care and management.



Responses were instantly projected to all attendees. After the responses were displayed there was opportunity for group discussion. The medical providers also have opportunity to submit questions for the ARS, and multiple doctors even asked unplanned questions during their presentations.

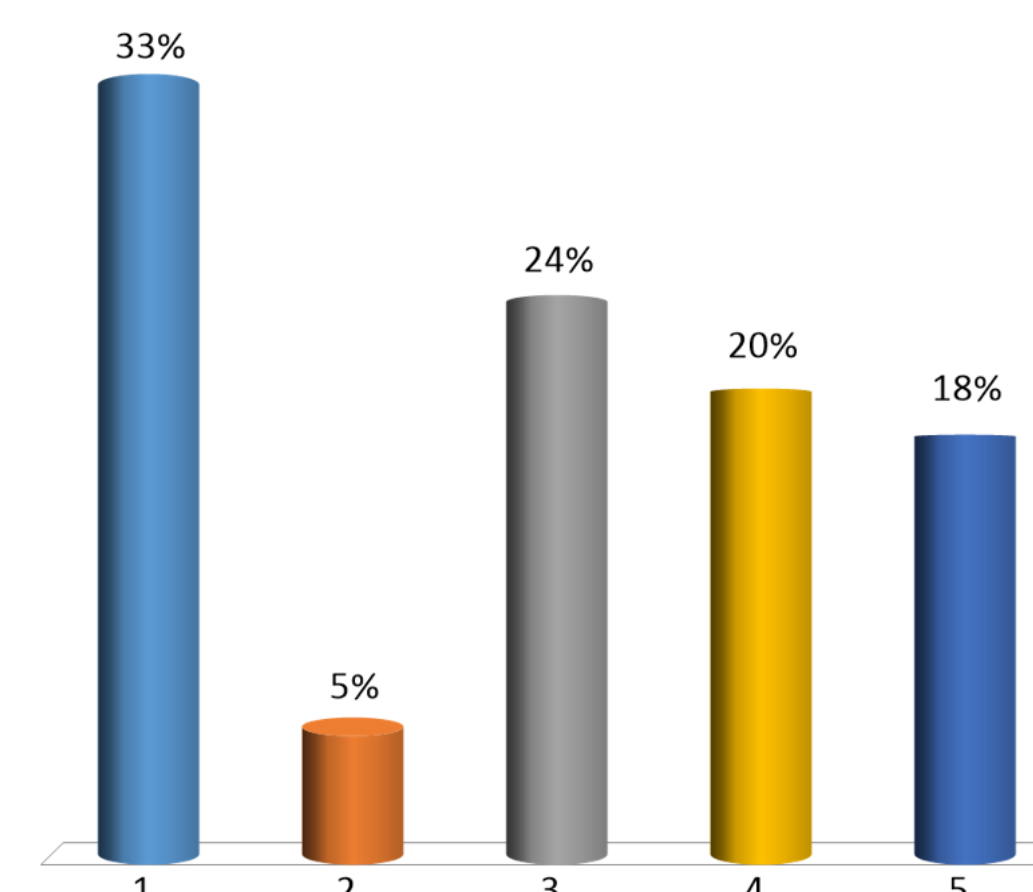


Results

Which of the following causes you the most difficulty?

1. Nosebleeds
2. GI Bleeding
3. Joint bleeds
4. Heavy Menstrual Bleeding
5. Other

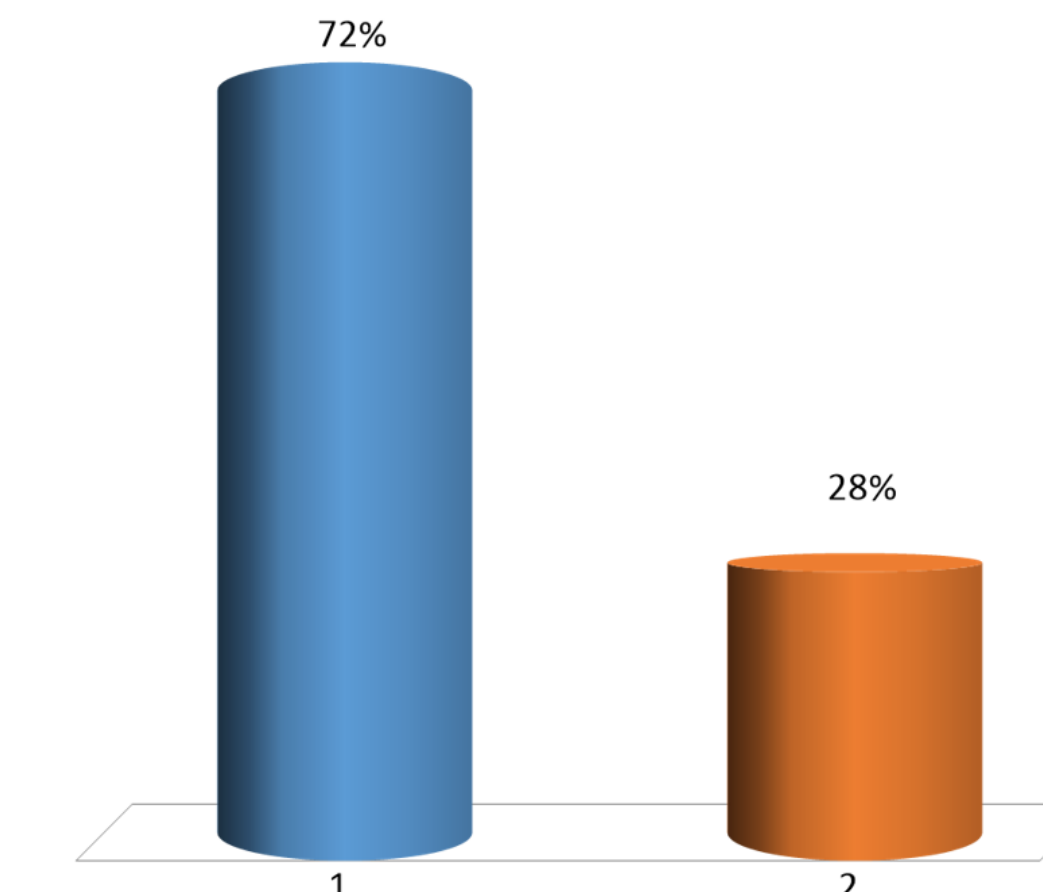
2019 ARS Response



Have you connected with a new person who you plan to continue contact with after the conference?

1. Yes
2. No

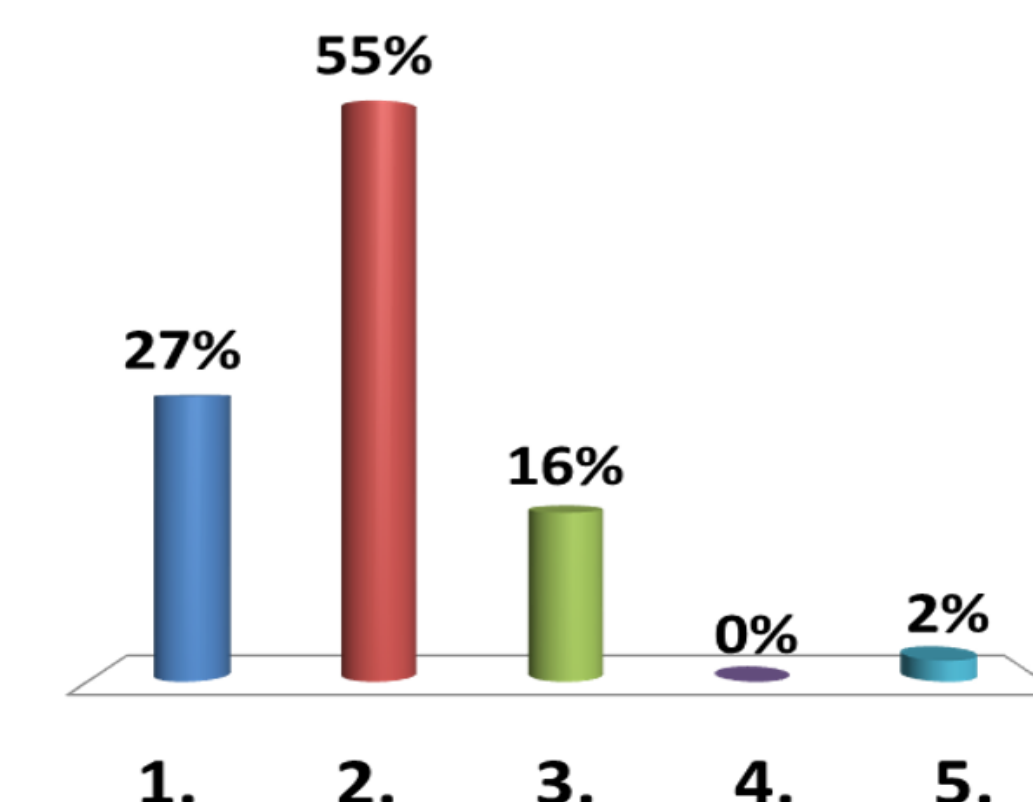
2019 ARS Response



How do you rate your knowledge of the medical aspects of Type 3 VWD?

1. Excellent
2. Good
3. Average
4. Poor
5. None

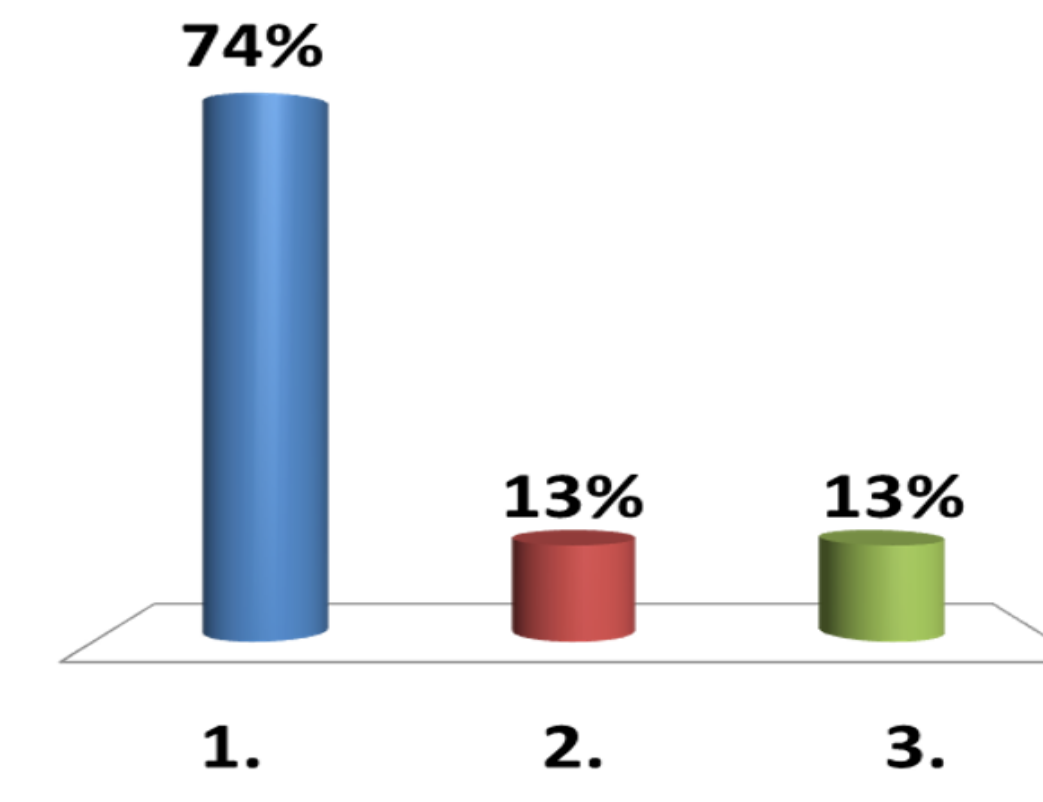
2018 ARS Results



When you registered you were asked what was one medical question you would like answered at this conference. Did you receive your answer?

1. Yes
2. No
3. No, but I know where to get the answer now

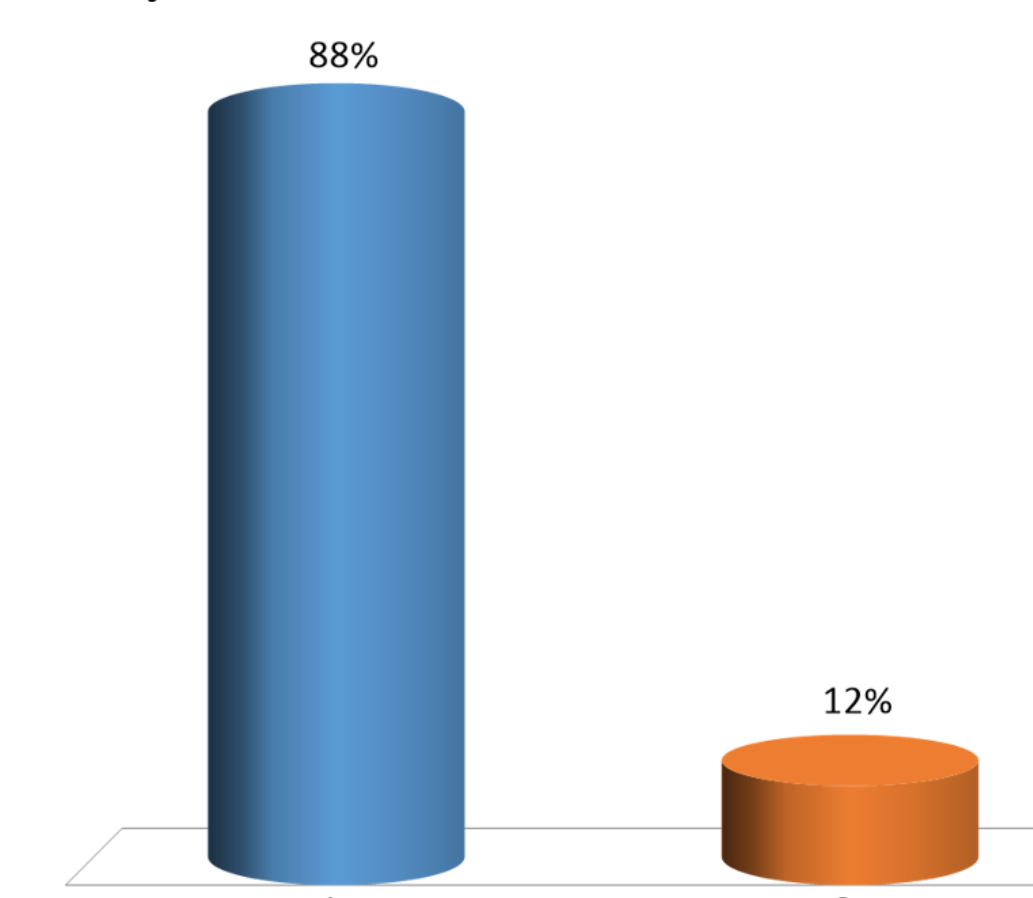
2018 ARS Results



Have you learned anything new at the conference that will improve your quality of life?

1. Yes
2. No

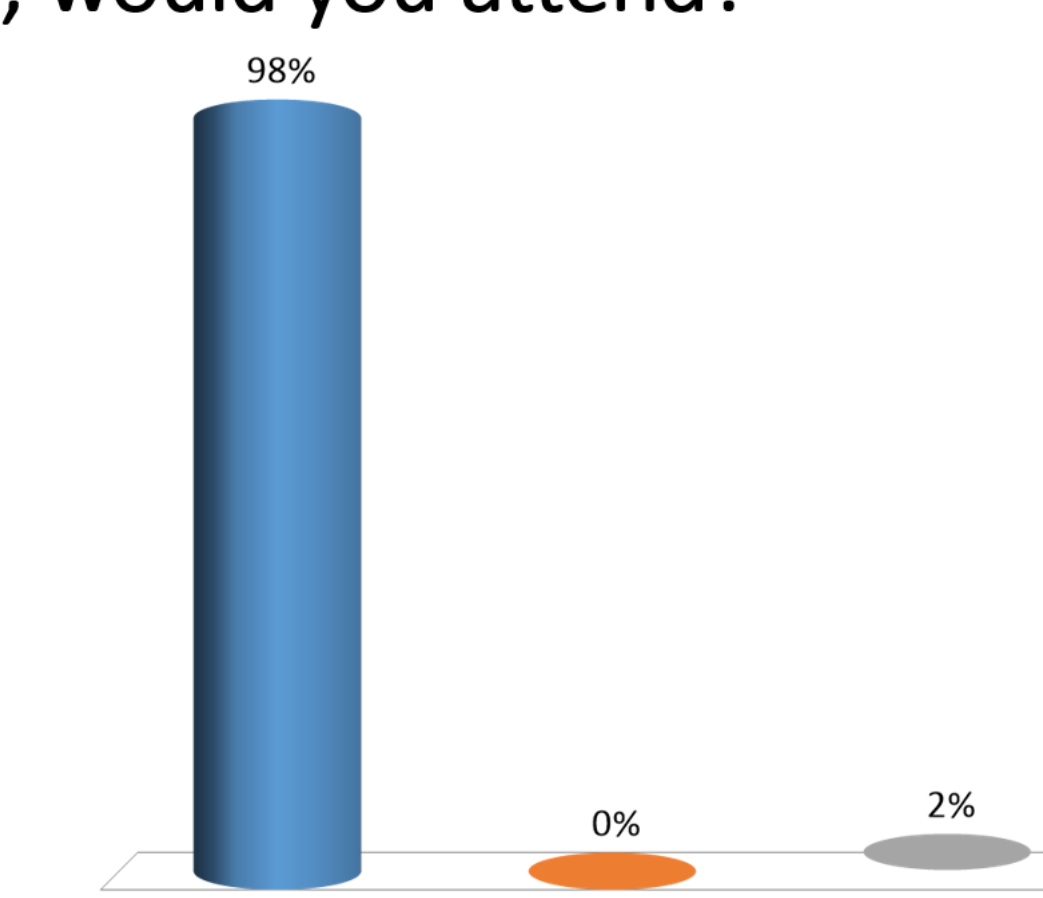
2019 ARS Response



If there is a 2020 National Type 3/Severe VWD Conference next year, would you attend?

- A. Yes
- B. No
- C. Not sure

2019 ARS Results



Discussion/Conclusion

There have been three annual Type 3/Severe VWD Conferences and each year there was on average a 90% participation using the ARS system. Since the responses were immediately projected, the information could be used by patients to evaluate whether others were experiencing the same symptoms, using different treatments and if they faced similar life challenges. Patients sharing collective experiences provided great insight for the Conference Faculty.

The participants clearly identified the desire to learn more even though in 2018 eight-two percent rated their knowledges as excellent or good. In 2018 seventy-four percent of respondents replied that they had received an answer to a medical question that they had on registration. In 2019 ninety-eight percent of participants responded they would attend the 2020 conference. Seventy-two percent responded their plan to remain connected with a person they met at the conference. Overwhelmingly in 2019 eighty-eight percent of respondents stated that they learned something new that would improve the quality of their life

The data obtained has been shared with the medical community through research posters, conference presentations and key stakeholder meeting presentations. The patients see their experiences being communicated and realize their voice is being heard.