# PSO 86

## Identification of Orthopedic and Genetic Needs Reported by Persons with Type 3/Severe Von Willebrand Disease

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**Submission Group**

Peer Support/Outreach/Integration Models

**Abstract**

Identification of Orthopedic and Genetic Needs Reported by Persons with Type 3/Severe Von Willebrand Disease Objective: To determine the medical and educational needs reported by persons with Type 3 and other severe types of Von Willebrand Disease (VWD) who attended the second USA National Type 3/Severe VWD Conference held in Florida in June 2018. Little research has been done concerning medical issues and education in Type 3/Severe VWD. As patient identification increases, it is vital that education, support and resources are available for these patients. Methods: A survey of 48 questions was developed and administered to 74 vetted patient attendees. Responses for any individual question varied between 62-66. The survey was administered through an Audience Response System (ARS) utilizing handheld clickers. The responses were compiled and immediately visually available to the respondents via a projector screen. The multiple-choice questions were used to identify basic demographics, medical and psychosocial concerns, and educational needs. Summary: In this self-reported ARS survey, basic demographic data was obtained. This sample of VWD patients reported a need for more education on several issues related to their medical and psychosocial issues including depression/mental health issues, lab results and product choices. In addition, subjects reported significant needs for care, treatment and education in the fields of orthopedic services and genetic counseling. Respondents' answers expressed a lack of orthopedic care despite a need for it. Only 8 (13%) patients reported having an orthopedic surgeon attend his/her bleeding disorder clinic. Forty-two (67%) did not know of any orthopedic resources. However, 18 (28%) reported that he/she had already had at least one joint surgery/procedure due to VWD and 5 (*%) plan to have surgery in the future. Eight (12%) had had joint replacements. Only 25 (40%) of respondents knew that they had undergone genetic testing related to their bleeding disorder, 30 (48%) have not had genetic testing, 8 (13%) were unsure. When asked, “Were your parents diagnosed with a bleeding disorder before your birth?” of the 63 who answered, 51 (81%) stated “no, neither parent”. When asked if a parent was diagnosed with a bleeding disorder after the respondent’s birth, 24 (38%) responded “yes” to one or both parents. Twelve (19%) respondents have had their diagnosis change since first being identified with a bleeding disorder. Conclusion: Orthopedic care, genetic testing and education are vital services wanted by Type 3/Severe VWD patients. The community should further evaluate these needs and take action to respond. These results may also empower persons with Type 3/Severe VWD to seek support from professional and social members of their community.