

## **Factors influencing uptake of evaluation among hemophilia carriers and potential carriers**

**Elizabeth Parks, Lauren Lichten, Michelle Alabek**

Boston University School of Medicine, Boston, Massachusetts

Introduction: Hemophilia A and hemophilia B are X-linked bleeding disorders that have been primarily seen as diseases affecting only males; however, there is increasing evidence to show psychological, medical, and reproductive advantages for women to know their carrier status. Aim: There is limited knowledge regarding why only some women seek evaluation regarding their hemophilia carrier status; as such, this study explores factors that influence the decision to pursue evaluation among hemophilia carriers and potential carriers. Methods: A cross-sectional study was conducted using a web-based quantitative survey. Women with a family history of hemophilia were recruited at the National Hemophilia Foundation Annual Meeting and via Hemo Friends Facebook and Hemophilia Foundation of Oregon Facebook pages. Correlations between factors and establishment of care were explored using comparative statistics Results: Sixty-nine hemophilia carriers and potential carriers were included in this analysis. Individuals with a personal history of bleeding symptoms (27/41) and individuals who required treatment for a bleeding event (18/22) had significantly higher rates of establishing care ( $p=0.041$ ,  $p=0.004$ , respectively). Individuals with a family history of severe hemophilia demonstrated higher levels of knowledge for hemophilia inheritance (24/34) and bleeding risks to carriers (12/30) ( $p=0.0007$ ,  $p=0.035$ , respectively); they were also more likely to discuss hemophilia with family members (27/34). Conclusion: The findings suggest that hemophilia carriers and potential carriers are more likely to establish care after experiencing bleeding symptoms. Hemophilia severity may impact the retention of knowledge and motivation to discuss with relatives. This has implications for healthcare providers in how they enhance and promote care for hemophilia carriers