

Executive Summary:

EHC Round Table on “Current Issues in von Willebrand Disease”

On September 10, 2024, the European Haemophilia Consortium (EHC) hosted its first post-pandemic Round Table on “Current Issues in von Willebrand Disease” in Brussels, Belgium. The event took place at the Warwick Hotel from 13:00 to 16:30, and was co-chaired by Miguel Crato, EHC President and Dr Maria Elisa Mancuso, Chair of the EHC Medical Advisory Group. The Round Table was attended by a total of 20 participants, representing a diverse group of stakeholders. This included EHC staff and Steering Committee members, National Member Organisation (NMO) representatives, and members of the EHC Von Willebrand Disease (VWD) Committee. In addition, third-party organisations such as the European Association for Haemophilia and Allied Disorders (EAHAD), clinicians, and industry representatives were present. The variety of attendees fostered rich discussions and allowed for a broad exchange of perspectives on the key challenges and opportunities in VWD care.

Session Highlights

The event commenced with a warm welcome and introduction from the co-chairs, setting the stage for an informative and interactive session.

1. Back to Basics & The Diagnostic Journey:

Dr Susie Shapiro, Consultant Haematologist at Oxford University Hospitals NHS Foundation Trust, provided a comprehensive overview of VWD. She highlighted the critical impact of the lack of diagnosis, the complex pathway to diagnosis, and the serious consequences of incorrect diagnoses. Dr Shapiro emphasised the importance of overcoming these challenges through better education for the general public, patients, and healthcare professionals, including primary care practitioners, gynaecologists, and haematologists.

Key points included the role of heavy menstrual bleeding and the use of bleeding assessment tools (self-BAT) to improve diagnosis, as well as the need for greater awareness around the different types of VWD. Dr Shapiro advocated for increasing public awareness through period-tracking apps that incorporate self-BAT recommendations and encouraging healthcare professionals to address menstrual health during routine consultations with women of reproductive age. She also stressed the importance of strengthening cross-border haematology networks and ensuring the availability of reliable diagnostic tests to support timely and accurate diagnoses.



2. Early Prophylaxis, Treatment Landscape & Access to Treatment:

Dr Maria Elisa Mancuso presented an overview of the general principles of treatment for VWD, focusing on both established and emerging treatment options. She discussed the indications for prophylaxis, particularly for patients with severe bleeding phenotypes, and stressed the importance of starting prophylaxis early in cases of joint bleeds to prevent long-term complications such as arthropathy. Drawing on lessons from haemophilia care, she stressed the importance of early intervention to prevent joint damage and called for continuous exploration of safe and efficacious therapeutic agents for VWD patients.

3. Patient Perspective:

Julia Rauscher, co-chair of the EHC VWD Committee, shared a personal account of her experiences with VWD, covering the broad spectrum of bleeding symptoms she has experienced, such as bruising, dental bleeds, heavy menstrual bleeding, nose bleeds, joint bleeds, ovarian cysts, and her late diagnosis. Her powerful story illustrated the ongoing challenges of accessing appropriate treatment, even after diagnosis, as she recounted a recent gynaecological bleeding emergency where she had to advocate for herself to be taken seriously. Julia emphasised that many of her bleeding events could have had better outcomes with the right treatment and care, underscoring the critical importance of patient education and self-advocacy. Her story highlighted the need for healthcare professionals to listen closely to patient experiences and ensure timely, appropriate interventions to manage the various bleeding symptoms of VWD.

4. Q&A Session:

The event concluded with a Q&A session, where attendees raised important questions and shared insights on the challenges surrounding prophylaxis for VWD. A key discussion point was the limited availability of prophylaxis for VWD patients, with attendees exploring the main obstacles to wider access. It was noted that bleeding phenotype and disease severity play a significant role, as some patients may experience frequent bleeding, while others may only have a couple of episodes per year. The challenge of administering prophylaxis every two days, as would be required for some patients, was also highlighted. Learning from haemophilia treatment models could provide valuable insights, but awareness among clinicians – especially regarding bleeding disorders in women – remains insufficient, necessitating further education and awareness-raising efforts.

Intermittent prophylaxis was discussed as a potential option, but missing data from patients not reporting all bleeding episodes and data-sharing challenges between hospitals were flagged as issues. Additionally, variations in how different European countries offer prophylaxis after a certain number of bleeds were noted, underscoring the need for standardised international guidelines on care. The importance of healthcare professionals actively listening to patient experiences was also emphasised.



Attendees shared examples of best practices, such as certain countries offering emergency prophylaxis doses for patients to keep at home or on hand. In Belgium, patients are provided with a card detailing their condition, treatment, factor levels, and relevant activities, which serves as a helpful tool in case of emergencies. These discussions underscored the ongoing need for more tailored and accessible prophylactic care for VWD patients across Europe.

The Round Table concluded with a synthesis of the discussions by Miguel Crato and Dr Mancuso, reaffirming the EHC's commitment to addressing ongoing issues in VWD care and encouraging collaborative efforts to improve access to treatment and patient support across Europe.

Travel Grant Initiative

This Round Table marked the pilot of a new EHC initiative aimed at providing travel grants to support National Member Organisations (NMOs). These grants covered up to €300 in travel costs for five NMO representatives, enabling wider participation. The grant selection criteria focused on current interest, advocacy efforts, or planned projects related to the topic of VWD. This initiative enabled participants from NMOs, who may not have attended previous Round Tables, to gain insights and contribute to the discussions.

Post-Event Survey

Attendees were invited to complete a post-event survey to evaluate the effectiveness of the sessions, the relevance of the topics covered, and the overall experience of participants. Following the event, 12 out of the 20 attendees responded to the post-event survey, with an overall rating of 4.6. Participants praised the content, with comments such as "The content was superb," "Clear, very interesting speakers," and "Insightful talks." All three individual sessions were rated as "excellent", reflecting the high quality of the presentations. Attendees particularly appreciated hearing the patient perspective, which added valuable real-world insight to the discussions. The positive feedback will help guide future EHC Round Tables, ensuring they continue to meet the needs of the bleeding disorder community.

Q2 How would you rate the Round Table overall?

Answered: 12 Skipped: 0

4.6 ★
average rating



Conclusion and Acknowledgements

The EHC Round Table on “Current Issues in von Willebrand Disease” successfully fostered meaningful dialogue among healthcare professionals, patients and patient advocates, third-party organisations, and industry representatives, addressing key challenges in diagnosis, treatment, and patient care. The event emphasised the importance of education, awareness, and collaboration to improve outcomes for VWD patients across Europe. The EHC extends its heartfelt thanks to CSL Behring and Sobi for their generous sponsorship, which made this important gathering possible and contributed to the advancement of discussions on improving care for people living with VWD.

