

Executive Summary

EHC Round Table on “Advancing Women’s Health – the Importance of Early Diagnosis for Women with Bleeding Disorders”

On March 25, 2025, the European Haemophilia Consortium (EHC) hosted its first Round Table on “*Advancing Women’s Health – the Importance of Early Diagnosis for Women with Bleeding Disorders*” back in the European Parliament in Brussels, Belgium. The event took place from 13:00 to 14:30, and was co-chaired by MEP Stine Bosse and Miguel Crato, President of the European Haemophilia Consortium. The Round Table was attended by a total of 30 participants, representing a diverse group of stakeholders. This included EHC staff, Steering Committee members, Women and Bleeding Disorders Committee members and National Member Organisation (NMO) representatives. In addition, third-party organisations, clinicians, and industry representatives were present. The variety of attendees fostered rich discussions and allowed for a broad exchange of perspectives on the importance of early diagnosis for women with bleeding disorders.

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. Embedding Women’s Health in EU policy:

In her opening statement, MEP Stine Bosse shared her personal experiences and emphasized the need for more robust EU policies focused on women’s health. Key points included the need to close the persistent gaps in representation, research, and clinical trials, and highlighted the complexity of women’s health. Drawing on lessons from other areas, she advocated for increased awareness, improved education, and equal access to treatment for all women and girls affected by bleeding disorders.

2. Treating women with bleeding disorders - new challenges and old stereotypes:

Dr Roseline d’Oiron from Hôpital Bicêtre, APHP, Université Paris Saclay, gave a presentation on *Treating Women with Bleeding Disorders – New Challenges and Old Stereotypes*. She presented an overview of the common experiences of women with bleeding disorders and drew attention to the heightened risks of excessive bleeding following surgeries, trauma, and the distinct challenges posed by menstruation and pregnancy.



Dr. d’Oiron noted that significant disparities continue to exist in access to diagnosis, treatment, and care, often stemming from a lack of knowledge among both patients and healthcare providers. She pointed out that women and girls with haemophilia are typically diagnosed six years later than men and boys. She emphasized the importance of early diagnosis, self-advocacy as well as the need to empower young girls, alongside further research and better data collection to improve care standards.

In concluding her presentation, Dr. d’Oiron stressed the necessity of improving education for healthcare professionals to help them identify abnormal bleeding symptoms and refer patients to haemostasis specialists promptly. She also advocated for a multidisciplinary care approach, involving both gynecologists and hematologists, to ensure that women and girls with bleeding disorders receive the comprehensive and timely care they deserve.

3. Lived experiences and barriers to care for women with bleeding disorders:

Two members of the EHC Women and Bleeding Disorders Committee shared their personal accounts of their experiences with bleeding disorders, providing an important patient perspective on the impact of bleeding disorders on daily life. Marion Bräuer’s powerful story illustrated how treatment, education, and the support of the family can enable one to live a satisfying life. Anna Tollwé shared with the audience how her delayed diagnosis has impacted her life and the difficulties she encountered, highlighting the need for greater awareness, comprehensive care, and specialised gynecological support for women with bleeding disorders.

4. Q&A Session:

During the Q&A session, participants engaged in a lively discussion about improving care for women with bleeding disorders. The conversation focused on the importance of integrating comprehensive care centers and gynecologists into treatment plans. The challenges of ageing in women with bleeding disorders were also highlighted, noting that while some mild conditions may improve over time due to increased factor levels, continued comprehensive monitoring is still crucial. Some participants also shared their own personal testimonies further emphasizing the importance of early diagnosis and self-advocacy.

The Round Table concluded with a synthesis of the discussions by Miguel Crato, reaffirming the EHC’s commitment to addressing ongoing issues in care of women and girls with bleeding disorders and encouraging collaborative efforts to improve access to treatment and patient support for women and girls across Europe.

Conclusion and Acknowledgements

The EHC Round Table on “Advancing Women’s Health – The Importance of Early Diagnosis for Women with Bleeding Disorders” 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 for women and girls living with bleeding disorders. The event emphasised the importance of education, awareness, and collaboration to improve outcomes for women with bleeding disorders across Europe. The EHC extends its heartfelt thanks to MEP Stine Bosse for hosting us at the European Parliament as well as CSL Behring and Takeda for their generous sponsorship, which made this important gathering possible and contributed to the advancement of discussions on improving care for women and girls living with bleeding disorders.

