

Executive Summary

EHC Round Table “Beyond the Diagnosis: Addressing Mental Health in the Bleeding Disorders Community”

On September 23, 2025, the European Haemophilia Consortium (EHC) hosted the Round Table entitled “*Beyond the Diagnosis: Addressing Mental Health in the Bleeding Disorders Community*” at Warwick Hotel in Brussels, Belgium. The event took place from 14:00 to 16:00, and was chaired by Olivia Romero Lux, CEO of the European Haemophilia Consortium. The Round Table was attended by a total of 19 participants, representing a diverse group of stakeholders. This included EHC staff, Steering Committee members, Mental Health Working Group members and National Member Organisation (NMO) representatives. Additionally, representatives from third-party organisations, clinicians, and the industry 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 chair, setting the stage for an informative and interactive session.

1. Mental Health in EU policy:

Opening the discussions, MEP András Tivadar Kulja (EPP, Hungary) shared a video message advocating for greater investment in psychological support for patients. He emphasised that such investment not only enhances individual well-being but also fosters a more compassionate Europe, underscoring the critical role of mental health within EU healthcare policy.

2. Bridging the gap: mental health support for people with bleeding disorders:

Dr Hermanas Ūsas, Psychiatrist at University Hospital Zürich, presented preliminary outcomes of the EHC Mental Health Survey, highlighting what he described as the often-overlooked burden of mental health challenges in individuals with bleeding disorders. He emphasised the biological causes of these challenges and their social consequences. His presentation also underscored the considerable gap between policy objectives and practical implementation, stressing the urgency of translating awareness into action and integrating positive psychology strategies into treatment frameworks.



3. Overcoming the stigma around mental health:

Amy Owen-Wyard, a Registered Mental Health Nurse and mother of a child with Glanzmann's Thrombasthenia, further addressed a key challenge within the community: confronting the stigma surrounding mental health and dismantling the barriers that often prevent patients and families from accessing psychological support. She noted that people with bleeding disorders might experience public stigma (negative stereotypes from society), self-stigma (shame and internalized beliefs), and structural stigma (barriers from policies or systems). She particularly highlighted the mental health challenges faced by carers and women.

4. Navigating mental health with bleeding disorders: access, awareness and support:

Scott McLean and Vasileios Kapouranis, members of the EHC Mental Health Working Group, shared both personal experiences and practical strategies. Scott described his transformative journey, highlighting how openly discussing his mental health challenges improved his quality of life. Vasileios underscored that living with a bleeding disorder encompasses more than physical health, emphasising that emotional well-being directly affects treatment adherence. He identified key areas for enhancing mental health care access, including overcoming resource constraints and barriers to specialised care, promoting accessibility, and recognising the essential role of community organisations. He emphasised that open discussions reduce stigma, education empowers patients and families, and peer support strengthens coping skills and confidence. In conclusion, both of the speakers highlighted that by improving access, raising awareness and strengthening support, we empower people with bleeding disorders to thrive.

5. Q&A Session:

During the Q&A session, participants engaged in a lively discussion about improving mental health care for people with bleeding disorders. The conversation focused on the importance of integrating comprehensive care centres and mental health specialists into treatment plans. Some participants also shared their own personal testimonies further emphasising the importance of peer-to-peer support. The round table reinforced that addressing mental health in bleeding disorders requires a comprehensive approach combining policy support, clinical expertise, stigma reduction, and community-driven solutions. As the discussions concluded, participants were reminded that mental health is healthcare, and the bleeding disorders community needs comprehensive support that addresses both physical and psychological well-being.

The Round Table concluded with a synthesis of the discussions by Olivia Romero Lux, reaffirming the EHC's commitment to addressing ongoing issues in mental health care for people with bleeding disorders and encouraging collaborative efforts to improve access to mental health care across Europe.



Conclusion and Acknowledgements

The EHC Round Table on “Beyond the Diagnosis: Addressing Mental Health in the Bleeding Disorders Community” successfully fostered meaningful dialogue among healthcare professionals, patients and patient advocates, third-party organisations, and industry representatives, addressing key challenges in mental health for people living with bleeding disorders. The event emphasised the importance of education, awareness, and support to improve mental health for people with bleeding disorders across Europe. The EHC extends its heartfelt thanks to CSL Behring and Takeda for their generous sponsorship, which made this important gathering possible and contributed to the advancement of discussions on improving mental health care for people living with bleeding disorders.

