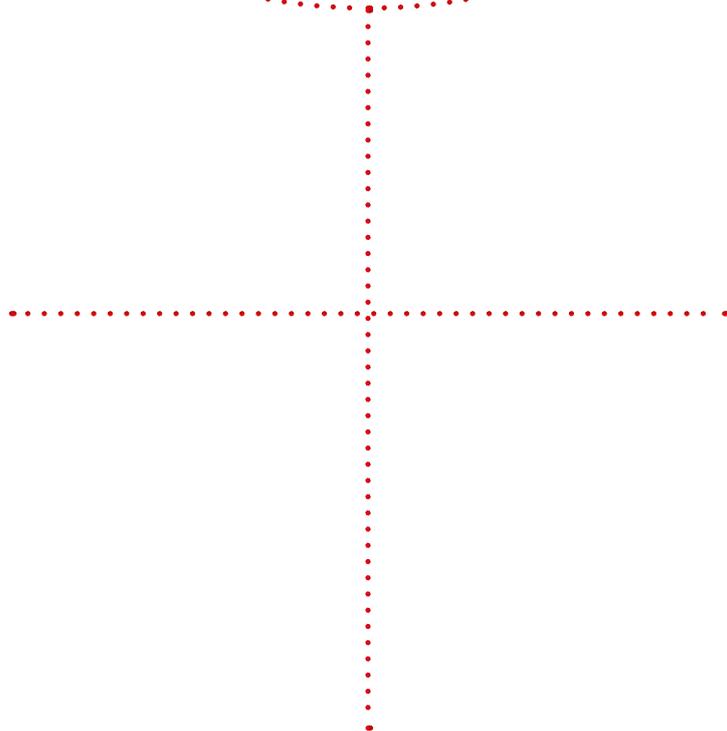
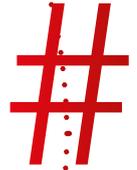


ANNUAL REPORT '25

EHC WOMEN AND
BLEEDING DISORDERS
COMMITTEE



ANNUAL REPORT '25

EHC WOMEN AND BLEEDING DISORDERS COMMITTEE

THE COMMITTEE

Our goals: Create awareness, recognition, support and education about and for women and girls in the bleeding disorders community.

We are there for: Women and girls with bleeding disorders, carriers and partners of people with rare bleeding disorders.

We meet: monthly online and in person when possible at various events in the bleeding disorders community. We stay in touch via email and WhatsApp, and share documents via Google Drive.

Our priorities are:

- Improve the general knowledge of women with bleeding disorders in the bleeding disorders community.
- Improve access to treatment and diagnosis of WBD.
- Highlight the link between infertility/fertility and bleeding disorders.

WORK

- Launched a **survey** for women and girls with bleeding disorders and their caregivers. It ran for two months, was offered in 12 languages, and received nearly 400 responses. Results are planned for release in 2026.
- Contributed to the **EHC Round Table** with MEP Stine Bosse in March 2025 in the European Parliament in Brussels, focusing on advancing women's health. Around 30 participants from a range of stakeholder groups joined. Discussions included treatment for women with bleeding disorders, lived experiences and barriers to care, and the place of women's health in EU policy.
- Participated in the EHC **Leadership Conference** in June 2025 in Brussels to support leadership growth across the community.
- Took part in the EHC **Annual Conference** in October 2025 in Vienna by leading a session on women's health and related barriers. Topics included diagnosis and counselling for women and girls, as well as management of menopausal age and symptomatic carriers.

Brina Zaman
Slovenia



Tatjana Marković
Serbia



Anna Tollwé
Sweden



Aleksandra Ilijin
Serbia



Bernadetta Pieczyńska
Poland



Yannick Collé
France



Ana Pastor
Portugal



Marion Bräuer
Austria



The work of the WBD Committee is supported by:

Zita Gacser

EHC Community & Projects Lead

Enea Atroce

EHC Project Assistant (Oct–Dec)

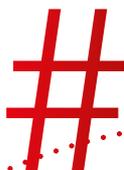
Stavroula Koukouzeli

EHC Project Assistant (Jan–Apr)

• in progress or still ongoing • finished | WBD = Women and Bleeding Disorders | WWD = von Willebrand Disease
EHC = European Haemophilia Consortium | NMO = National Member Organisation
EAHAD = The European Association for Haemophilia and Allied Disorders | WFH = World Federation of Hemophilia

Advocacy and Campaigns

- Ran an **International Women's Day** campaign on 8 March to highlight the experiences of women with bleeding disorders.



CREATE AWARENESS FOR WBD



EHC WOMEN AND BLEEDING DISORDERS COMMITTEE



Brand identity

- Developed a new brand identity that presents a clear and cohesive look with the aim of raising awareness and strengthening visibility.

EHC WOMEN AND BLEEDING DISORDERS COMMITTEE

Brand identity

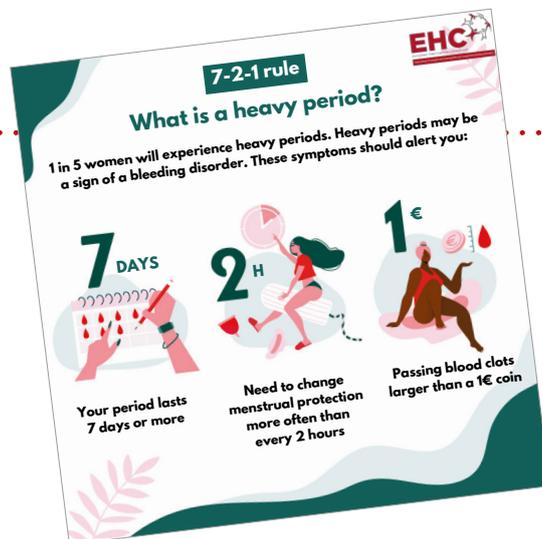
Anna Tollock & Marion Bräuer, 2025

Exchange

- Strengthened **cooperation** with other EHC committees, including ERIN and VWD, aiming to identify shared interests and shape joint projects.

Resources

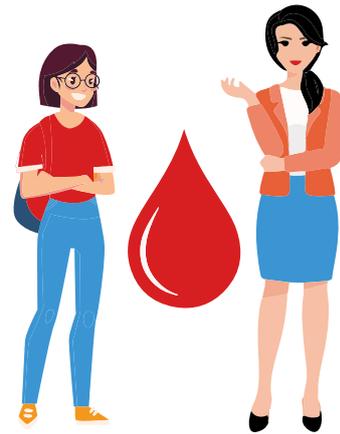
- More information and all resources can be found on: <https://community.ehc.eu/focus-area/wbd-women-with-bleeding-disorders/>



PRINCIPLES OF CARE

FOR WOMEN & GIRLS WITH INHERITED BLEEDING DISORDERS

Women and Girls with Bleeding Disorders (WGBD) face unique challenges. In order to **optimise diagnosis, care and management** of WGBD, the EAHAD Women and Bleeding Disorders Working Group have developed the following Principles of Care (PoC):



Equitable access and quality of care for all individuals with bleeding disorders, irrespective of gender



Inclusion of a dedicated obstetrician and gynaecologist in the multidisciplinary team



Provision of a patient-centred comprehensive management plan throughout pregnancy and the post-partum period



Timely and accurate diagnosis of bleeding disorders in women and girls



Education of WGBD and their families regarding the menstrual cycle and its management



Involvement of WGBD in registries, clinical research and innovation



Awareness of the additional challenges faced by WGBD throughout life



Early recognition and optimal management of heavy menstrual bleeding



Scan and read more.



Provision of comprehensive care in a family centred approach



Provision of pre-conception counselling and access to prenatal diagnostics

