

# ANNUAL REPORT '25

EHC WOMEN AND  
BLEEDING DISORDERS  
COMMITTEE

#



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## 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.

**Brina Zaman**  
Slovenia



**Anna Tollwé**  
Sweden



**Bernadetta Pieczyńska**  
Poland



**Ana Pastor**  
Portugal



### 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.

**Aleksandra Ilijin**  
Serbia



**Yannick Collé**  
France



**Marion Bräuer**  
Austria



#### The work of the WBD Committee is supported by:

**Tatjana Marković**, EHC Vice-President, Serbian NMO

**Zita Gacser**, EHC Community & Projects Lead

**Enea Atroce**, EHC Project Assistant (Oct–Dec)

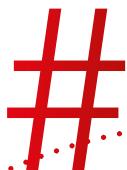
**Stavroula Koukouzeli**, EHC Project Assistant (Jan–Apr)

- in progress or still ongoing
- finished

WBD = Women and Bleeding Disorders | VWD = 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

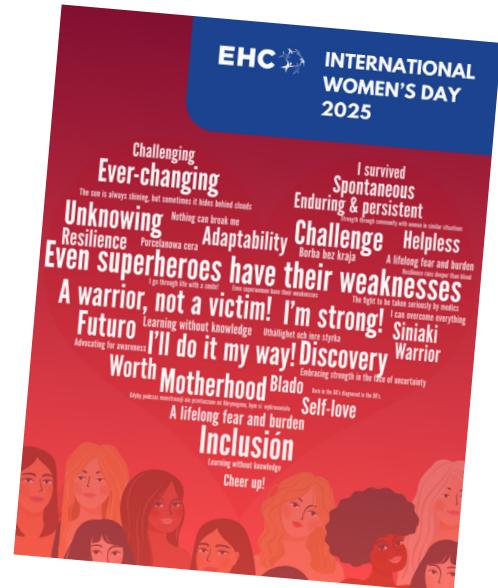


### Exchange

- 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/>



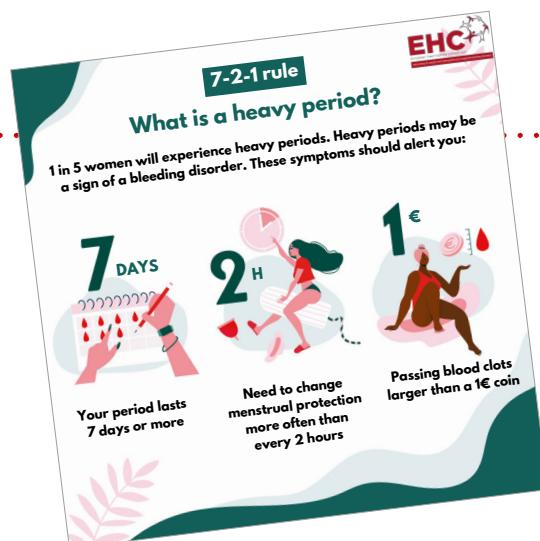
### Brand identity

- 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 Tolwé & Marlon Bräuer, 2025



# 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



Timely and accurate diagnosis of bleeding disorders in women and girls



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



Awareness of the additional challenges faced by WGBD throughout life



Early recognition and optimal management of heavy menstrual bleeding



Provision of comprehensive care in a family centred approach



Provision of pre-conception counselling and access to prenatal diagnostics



Involvement of WGBD in registries, clinical research and innovation



Scan and read more.

