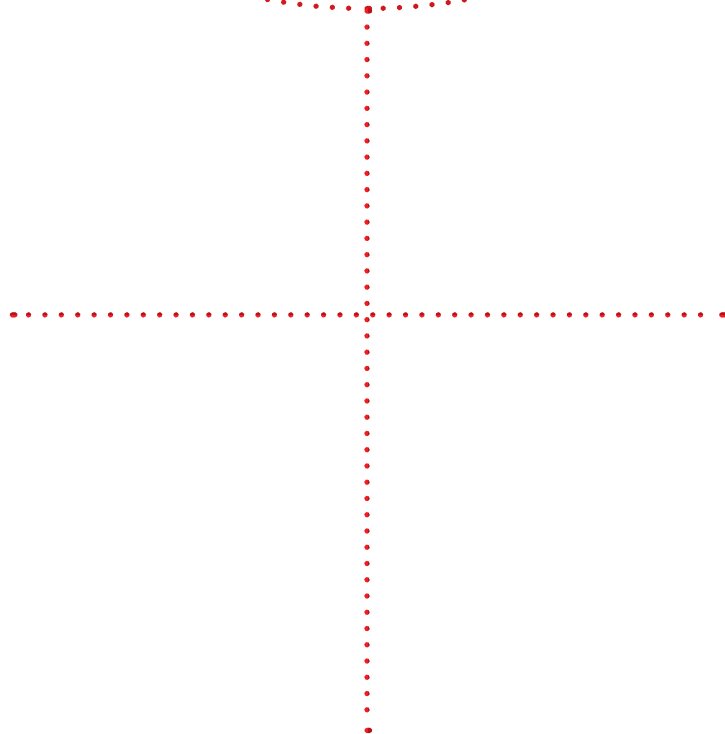
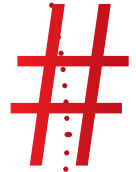


# ANNUAL REPORT '23

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 in the bleeding disorder community.

**We are there for:** Women 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

- We formed 2 working groups:
  - \* Ambassadors working group
  - \* Fertility group
- Retreat in May to set goals for this committee's work
- Ambassador meetings via Zoom
- Sessions at the EHC Leadership Conference in June
- Sessions at the EHC Annual Conference in October, including presentations on
  - Improving diagnosis and care pathways
  - Engaging women – Ambassadors update
  - Putting yourself first

**Karola Diósi**  
Hungary



**Tatjana Marković**  
Serbia



**Anna Tollwé**  
Sweden



**Ana Pastor**  
Portugal



**Yannick Collé**  
France



**Marion Bräuer**  
Austria



The work of the WBD Committee is supported by:

**Jo Eerens**, EHC Vice-President Finance, Belgian NMO

**Zita Gacser**, EHC Behavioural Change Lead

## Social Media Presence

- Regular updates on EHC social media channels
- Movie on PoC for WBD published on International Women's Day

# #

# CREATE AWARENESS FOR WBD



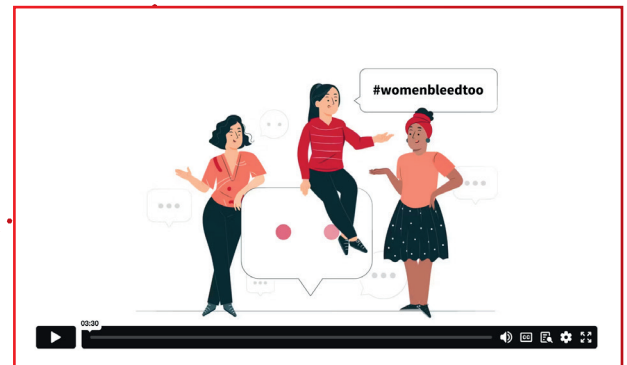
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## Movies & Podcasts

- Podcast episodes on Principles of Care: [soundcloud.com/european-haemophilia-consortium](https://soundcloud.com/european-haemophilia-consortium)
- Movie on PoC for WBD: [ehc.eu/the-ehc-marks-2023-international-womens-day/](https://ehc.eu/the-ehc-marks-2023-international-womens-day/)

## Outreach

- WBD Ambassador Group meetings
- Printing & sharing of PoC cards at EHC Conferences
- Meet & greet during break at the EHC conference



## Principles of Care (PoC) for Physiotherapy

The PoC list eight principles outlining optimum care standards for physical health.

## Principles of Care (PoC) for Women and Girls with bleeding disorders

The PoC list ten principles outlining optimum care standards for WGBD.

## Exchange

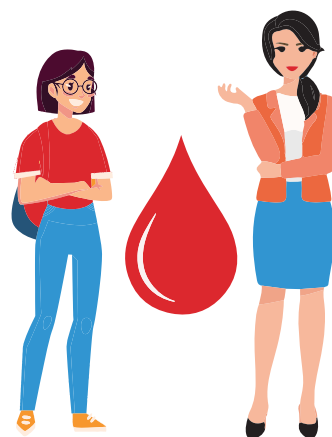
- WHF WGBD Summit,
- EHC conference, and
- Various other events.
- Plan to cooperate closer with the other EHC committees.



# 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



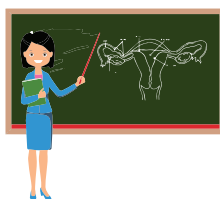
Inclusion of a dedicated obstetrician and gynaecologist in the multidisciplinary team



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

