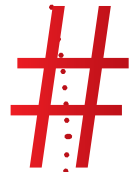


ANNUAL REPORT '21

EHC WOMEN AND
BLEEDING DISORDERS
COMMITTEE



ANNUAL REPORT '21

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 mail and WhatsApp and share docs via 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

- Due to the pandemic, we decided to do five webinars on the following topics:
 - Advocacy 101
 - Partnering up in the NMO
 - Partnering up & raising awareness with healthcare professionals
 - Preparing for menarche
 - Fertility and bleeding disorders
 - Preparing for older age
 - Psychosocial issues for WBD
 - Impact of bleeding disorders on sexual health and intimacy
 - Starting a family: How to tackle genetic counselling?
 - Focus on treatment protocols for WBD and underdiagnosis and recognition
 - Registries & WBD
- Preparation of the European Conference on Women and Bleeding Disorders on 19-22 May 2022 in Basel, Switzerland and online ("hybrid")

Karola Diósi
Hungary



Tatjana Marković
Serbia



Anna Tollwé
Sweden



Diana Lighezan
Romania



Yannick Collé
France



Katja Peltoniemi
Finland



Evelyn Grimberg
The Netherlands



Marion Bräuer
Austria



CREATE AWARENESS FOR WBD

EHC WOMEN AND BLEEDING DISORDERS COMMITTEE

Social Media Presence

- Regular updates on EHC Social Media Channels.
- Continued the #caughtredhanded campaign virtually.

#caughtredhanded



#caughtredhanded



Movies & Podcasts

- Video on WBD and joints
- Preparation of podcasts concerning topics for women and girls with bleeding disorders, publication 2022



Outreach

- Five webinars covering different topics with experts, healthcare professionals and patient representatives



Changes

- + Karola Diosi
- + Marion Bräuer
- Naja Skouw-Rasmussen
- Ana Pastor

Principles of Care (PoC) for Physiotherapy

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

Outreach

- WHF Summit,
- EHC conference, and
- Various other events.

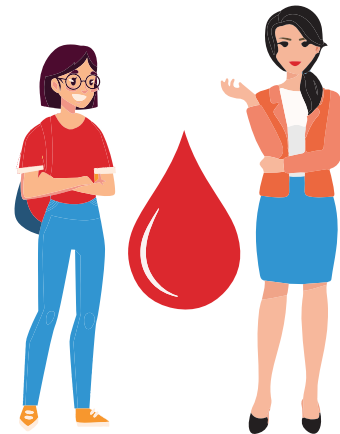
Collaborations

- Representation at the **EAHAD** working group to promote Principles of Care for Women with Bleeding Disorders.
- Regular contact with **WFH** WBD Group.
- We took part in **EAHAD**'s work to develop a set of European Principles of Care for Physiotherapy Provision for People with Bleeding Disorders: perspectives of physiotherapists & patients.

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

