

EHC WOMEN AND BLEEDING DISORDERS COMMITTEE

About women with a bleeding disorder

When talking about women with a bleeding disorder, we refer to women who have a genetic mutation impacting their coagulation, whether they are symptomatic or not. The aim of this Committee is to gather people with a keen interest in promoting and raising awareness about issues related to women and bleeding disorders.

Role

The role of the Women and Bleeding Disorders Committee of the European Haemophilia Consortium (EHC) is to create awareness, recognition, support and education about, and for, women in the bleeding disorder community at European level. The Committee will provide advice to EHC members, volunteers and staff in matters concerning women with bleeding disorders.

Composition

The EHC Women and Bleeding Disorders Committee shall be composed of no more than 9 persons:

EHC structures:

- One EHC Steering Committee member,
- One EHC Staff member,

Volunteers:

- Two women with bleeding disorders caused by factor deficiency (for e.g. von Willebrand, haemophilia or any other rare factor deficiencies) who experience moderate to severe bleeding symptoms,
- One woman with a bleeding disorder (see above) who does not experience bleeding symptoms,
- One woman with a platelet disorder,
- One parent of a girl with a bleeding disorder,
- One volunteer working on women's issues,
- One volunteer with additional experience to support the work of the Committee.

To a large extent the Committee will seek expertise from the EHC Medical Advisory Group (MAG) and EHC Medical and Scientific Advisory Group (MASAG). When needed, the Committee may consult additional external experts on particular issues.

Eligibility

The members shall:

- Be members of or have a strong professional link with one of the EHC National Member Organisations (NMO),
- Be fluent in English,
- Commit to dedicate enough time to fulfil the activities carried out by the Women and Bleeding Disorders Committee. The estimated time needed is one hour per week, plus one 1-hour online meeting per month, plus one face-to-face meeting per year in combination

with a conference. The workload may require the ability to work on short notice and to meet tight deadlines.

- Have experience at either national or international level in carrying out activities and representing women in the bleeding disorder community.

Selection process and mandate:

The above members of the EHC Women and Bleeding Disorders Committee shall be selected as follows:

- An open call for volunteers will be sent out to EHC NMOs, the volunteers shall be selected on the basis of meeting the above criteria and on the quality of their applications. Selected candidates will be appointed by the EHC Steering Committee for a period of two years.
- The EHC Steering Committee Member shall be appointed by the EHC Steering Committee for a period of three years,
- The EHC staff member shall be appointed by the EHC Chief Executive Officer for a period of three years,

The EHC Women and Bleeding Disorders Committee shall appoint a chair with a mandate of three years, who will be responsible for leading the work of the Committee. (The Chair shall meet with the EHC Steering Committee once a year to report on the Committee's activities.)

If any member of the Women and Bleeding Disorders Committee should resign during his/her mandate, the committee shall identify a suitable replacement in the two months following the resignation to fill the position with a candidate meeting the criteria of the open position.

If any member of the Women and Bleeding Disorders Committee does not attend three consecutive meetings in a row without prior notice and a reasonable explanation, the Committee shall have the discretion to remove his/her membership.

Created and approved - October 2022