

Brussels, 13 December 2024

**To:** EHC National Member Organisations

**Subject:** Call for volunteers to join the EHC Women and Bleeding Disorders Committee

Dear NMOs,

The European Haemophilia Consortium (EHC) is currently looking for one (1) volunteer to join its Women and Bleeding Disorders (WBD) Committee for the remaining period of the current three-year term (2023-2025).

This Committee has been established to create awareness, recognition, support and education about, and for, women in the bleeding disorder community at the European level. The Committee provides advice to EHC members, volunteers and staff in matters concerning women with bleeding disorders.

The EHC is currently looking for:

- One (1) volunteer who either has a bleeding disorder or is a relative/caregiver of a person with a bleeding disorder.

The ideal candidate will:

- Be a member 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 WBD Committee. The estimated time needed is one hour per week, plus one hour of online meeting per month, plus one full day face-to-face meeting per year. 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.

To apply for this position, candidates need to send:

- The candidate's CV, outlining in particular relevant experience such as volunteering,
- A motivation letter outlining briefly their background and why they are interested in joining the EHC Women and Bleeding Disorders Committee,

- A letter of recommendation from the NMO President outlining why they believe the candidate would make a great addition to the EHC Women and Bleeding Disorders Committee.

Applications should be sent to [zita.gacserl@ehc.eu](mailto:zita.gacserl@ehc.eu) by **9 January 2025** at the latest.

In attachment, you will find the Terms of Reference further outlining the Committee's objectives and the volunteer recruitment process. The candidates will be reviewed and selected by the EHC Steering Committee based on the criteria outlined above.

If you have any additional questions about this call for candidature, please do not hesitate to contact the EHC office.

Sincerely,



Miguel Crato  
EHC President

## **EHC WOMEN AND BLEEDING DISORDERS COMMITTEE**

### **TERMS OF REFERENCE**

#### **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 (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). 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. The selected candidate will be appointed by the EHC Steering Committee for a period of one year.
- 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

Revised – November 2024