

October 31st 2022

About non-severe bleeding disorders

Beyond the medical classification between mild, moderate and severe in bleeding disorders (BD), the question of how to accompany a person living with a non-severe BD is a challenge, with non-severe referring to those not facing every day the burden of the disease from a medical perspective (treatment, medical follow-up). More than $\frac{2}{3}$ of the people with a BD has a non-severe phenotype and have historically been underserved by the EHC. Also with the advancement of haemophilia therapeutic options and increased access, at least in most EU countries, people with severe haemophilia (PWH) will move into milder bleeding categories. Hence the number of non-severe will increase.

The aim of the Non-severe Bleeding Disorders Committee is to gather people with a keen interest in promoting and raising awareness about issues related to people with non-severe bleeding disorders.

Role

The proposed role of this committee is to create awareness, recognition, support and education about and for people with non-severe bleeding disorders in Europe, both internally within the EHC and its community, as well as externally amongst broader stakeholders.

Composition

This committee shall have a mandate of three years and be composed of no more than ten (10) persons, as follows:

EHC structures:

- One (1) EHC Steering Committee member
- One (1) EHC staff member

Volunteers:

- At least one (1-2) patient with non-severe haemophilia
- At least one (1-2) patient with non-severe VWD
- At least one (1-2) patient with a non-severe RBD
- At least one (1-2) healthcare provider

To a large extent this body will seek expertise from the EHC Medical Advisory Group (MAG) and EHC Medical and Scientific Advisory Group (MASAG), and when needed, consult external experts. The EHC staff and chair will liaise with the other EHC Committees to ensure that non-severe issues of WBD, VWD, etc., are taken into consideration.

Eligibility

Applicants must be:

- Members of, or having strong professional links with, an EHC NMO
- Deep awareness of the issues facing mild and non-severe bleeding disorder patients
- Fluent in English
- Committed to dedicating sufficient time to fulfil the activities required by the group, including on short notice and with a tight deadline
- Experienced at either national or international level in carrying out activities or representing the non-severe in bleeding disorder community

Selection process and mandate:

Applicants to the above body shall be selected as follows:



- By written application to an open call for volunteers, sent to EHC NMOs
- Based on meeting the above criteria, the quality of their motivation letter, and the quality of the NMO letter of recommendation
- Selected and/or appointed by the EHC Steering Committee (SC)

Once established, the body itself shall appoint its chair with a mandate of three years, who will be responsible for leading the work of the group and reporting back to the EHC SC once a year.

If any member of the Non-severe 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 for the remainder of the term.

If any member of the group does not attend three (3) consecutive meetings in a row without prior notice and a reasonable explanation, the group shall have the discretion to revoke their membership.

