

EAHAD von Willebrand Disease Working Group

Terms of Reference

1. Purpose and goals

- Raising awareness of VWD among healthcare professionals and the public.
- Understanding the epidemiology and global impact of the disease.
- Characterizing the demographics and clinical bleeding profiles of affected individuals.
- Investigating laboratory phenotypes and the genetic basis of VWD.
- Evaluating treatment strategies and their impact on patients' quality of life.

2. Membership

- The Working Group will include at least four (4) members from at least three (3) different European countries and a maximum of thirteen (13) members and one (1) patient representative.
- The Working Group could invite co-opted members as observers based on their expertise and needs of the different projects.
- The Working Group members must be experts in the field of von Willebrand Disease care and able to substantially contribute to support EAHAD.
- The Working Group members must be members of EAHAD.
- The Chair will be appointed by the EAHAD Executive Committee. A Vice-Chair can be nominated by the Working Group to provide assistance to the Chair and replace the Chair in his/her absence.
- The original composition of the Working Group will be discussed with the Executive Committee and the Chair of the Working Group.
- The Working Group will include at least one EAHAD Executive Committee member.
- When a vacancy arises or a new need in one or another specific field is identified in the Working Group, a call for new members will be published on the EAHAD website and circulated via EAHAD's social networks. Existing members will review the applications. Agreement within the Working Group is desired and a majority of members of the Working Group must agree on the appointment of a new member. In case of a tie, the Chair has the deciding vote.
- Members of the Working Group will have a term of two (2) years with possibility of one (1) year extension and can be re-elected.

3. Duration of the mandate

- The Working Group will have a fixed term mandate of two (2) years. After that period, the mandate term will be re-evaluated by the Executive Committee, based on goals, objectives, and deliverables.
- The Chair will rotate in a mandate of two (2) to three (3) years and can be re-elected.

4. Frequency of Meetings

- Maximum of five (5) meetings per year. The meetings will be in-person or virtual.
- In-person meetings should, when possible, be organised to coincide with other meetings (e.g. the annual congress).
- All Working Group Members are required to actively participate in the work of the Working Group and attend at least 60% of the Working Group meetings.
- At least one staff representative from the EAHAD Office will attend the meetings and help with the preparatory work, the minutes and reporting.

5. Funding

- Meetings and support by the EAHAD Office will be funded by EAHAD with possible external support according to the EAHAD Sponsorship Policy.
- The annual budget is 15,000 EUR.
- The funding will cover in-person meetings, teleconferences, publication fees, IT support, etc.

6. Reporting requirements

- The Working Group will produce reports outlining its progress on agreed objectives. The reports will be submitted to the Executive Committee. A summary will be included in the EAHAD annual report.
- Minutes will be drafted and distributed to Working Group members after the meeting date.

7. Dissemination activities

- The Working Group will support the dissemination of its activities by providing content to the EAHAD staff to share via the EAHAD website and social media channels.
- Publications and presentations by the Working Group are encouraged.
- Any publications should acknowledge the Working Group and all its members.

8. Review of the terms of reference

- The Working Group will review the terms of reference every two (2) years

September 2025