

## **EAHAD Very Rare Coagulation Factor Deficiencies Working Group**

### **Terms of Reference**

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#### **1. Purpose and goals**

The main purpose of this working group is to establish and maintain a European network of health care professionals, laboratory scientists and patient representatives with expertise in very rare coagulation factor deficiencies to raise awareness of these bleeding disorders and facilitate scientific research in order to improve the level of healthcare for this part of the community.

The Working Group's goals are:

- To extend knowledge of patients with very rare coagulation factor deficiencies with focus on demographics, clinical bleeding phenotype, laboratory phenotype, genotype characterization, treatment strategy and quality of life.
- To improve the level of healthcare, including diagnosis, genetic counseling and treatment in patients with very rare coagulation factor deficiencies.
- To define research priorities with the aim to reach all areas in Europe, independent of the socio-economic background.
- To facilitate educational sessions for the EAHAD community.

#### **2. Membership**

- The Working Group will include at least seven (7) members from at least three (3) different European countries and a maximum of ten (10) members, including a patient representative from the European Haemophilia Consortium (EHC).
- The Working Group can invite co-opted members as observers based on their expertise and the needs of different projects.
- The Working Group members will all have their individual expertise in the field of very rare coagulation factor deficiencies.
- The Chair and the Vice Chair will be assigned by the Working Group, and both members will be recognized by the EAHAD Executive Committee as such.
- The Working Group will include at least one EAHAD Executive Committee member and one patient's representative designated by the EHC.
- When a vacancy of a new member arises in the Working Group, a call for a new member will be published on the EAHAD website and the existing members will review the applications. In case there are more applications than available slots, the existing members will vote and, in case of a tie, the Chair will have the deciding vote.

### **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.

### **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
- 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 10,000 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 on 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

**April 2024**