

## **EHC YOUTH COMMITTEE TERMS OF REFERENCE**

### **Role**

The Youth Committee develops the programme, organises and implements the Youth Leadership Workshop of the European Haemophilia Consortium (EHC) that takes place annually on dates and locations set by the EHC Steering Committee. The members of the Youth Committee also advise the EHC Steering Committee, the EHC Medical Advisory Group and the EHC staff on youth strategies and initiatives.

Members of the Youth Committee shall attend and actively participate in:

- All meetings and conference calls relevant to the preparation of the Youth Leadership Workshop,
- The Youth Leadership Workshop.

Members of the Youth Committee may be requested to attend individually or collectively the following events to provide input on the youth-related activities and to ensure that the EHC Youth Strategy is coherent throughout all EHC areas of work:

- The EHC Annual Conference,
- The EHC Leadership Workshop,
- Any other relevant EHC event upon request from the EHC Steering Committee,
- Youth-related events organised by third parties upon request by the EHC Steering Committee.

### **Composition**

The EHC Leadership workshop shall be composed of:

- One to two EHC Steering Committee Members,
- One to two EHC Staff members,
- Up to three youth volunteers,
- One advisor.

### **Eligibility**

Youth volunteers shall:

- Be between 21 and 30 years of age at the time of nomination,
- Be a member of one of the EHC National Member Organisations (NMO),
- Be a patient or carrier of one of the bleeding disorders covered by the mandate of the EHC **OR** be the sibling or child of a person with a bleeding disorder covered by the mandate of the EHC,
- Be fluent in English,
- Have been an active NMO volunteer for at least three years,
- Be committed to dedicating enough time to fulfil the activities carried out by the Youth Committee.

Advisors shall:

- Be over 30 years of age at the time of the nomination,
- Be a member of one of the EHC National Member Organisations (NMOs),
- Be a patient or a carrier of one of the bleeding disorders covered by the mandate of the EHC **OR** be the sibling, child, parent or caretaker of a person with a bleeding disorder covered by the mandate of the EHC,
- Be fluent in English,
- Have been an active NMO volunteer for at least three years with a demonstrated interest in youth-related activities,

- Be committed to dedicating enough time to fulfil the activities carried out by the Youth Committee.

**Selection process and mandate:**

The Youth Committee members shall be selected as follows:

- EHC Steering Committee members serving on the Youth Committee shall be appointed by the full EHC Steering Committee for a period of three years,
- EHC staff members shall be appointed by the EHC Chief Executive Officer for a period of three years,
- EHC youth volunteers shall be appointed by the existing EHC Youth Committee for a period of three years,
- EHC advisors shall be appointed by the existing EHC Youth Committee for a period of three years.

The EHC Youth Committee shall appoint a chair from its youth volunteers. The Chair shall have a mandate of three years. The Chair of the Youth Committee shall meet with the EHC Steering Committee once a year to report on the Committee's activities.

If any member of the EHC Youth Committee resigns during his/her mandate, the EHC shall open a call for candidatures in the two months following the resignation to fill the vacant position.