

EHC INHIBITOR WORKING GROUP

TERMS OF REFERENCE

Role

The Inhibitor Working Group will be responsible for developing, approving and helping to implement the content and the programme of the European Inhibitor Network (EIN) initiative in accordance with the project description provided by the EHC. The working group members will also be in charge of promoting the EIN programme and attracting participants to its various elements, as well as identifying the potential experts to contribute to the content of the programme.

Members of the Inhibitor Working Group shall attend and actively participate in:

- Conference calls relevant to the planning and implementation of the activities of the EIN initiative;
- A face-to-face planning meeting of the Inhibitor Working Group once per year;
- EHC Workshops / Round Tables related to inhibitors, as necessary or relevant;
- Discussion groups within the on-line community;
- EHC Inhibitor Summit.

Members of the working group may be requested to individually or collectively attend the following events to provide input on the EIN initiative and exchange experiences:

- Inhibitor-related events organised by the NMOs upon their invitation and approval of the EHC Steering Committee,
- Inhibitor-related events organised by third parties upon request by the EHC Steering Committee.

Composition

The EHC Inhibitor Working Group shall be composed of no more than 12 persons:

EHC structures:

- One EHC Steering Committee member,
- One to two EHC MAG members,
- One to two EHC Staff members,

Volunteers:

- Two to three persons with haemophilia who have inhibitors of different ages and backgrounds,
- One to two parents of persons with haemophilia who have inhibitors with children of different ages,
- One professional in the field of caregiving,
- One physiotherapist or other health care specialist.

Eligibility

The volunteers shall:

- Be members or have a strong professional link with one of the EHC National Member Organisations (NMO),
- Be fluent in English,
- Have capacity for networking and promoting the message and activities of the European Inhibitor Network initiative,
- Commit to dedicate enough time to fulfil the activities carried out by the Inhibitor Working Group.

Selection process and mandate:

The Inhibitor Working Group members shall be selected as follows:

- EHC Steering Committee Member(s) shall be appointed by the EHC Steering Committee for a period of three years,
- EHC Medical Advisory Group Member(s) shall be appointed by the EHC Steering Committee for a period of three years,
- EHC staff member(s) shall be appointed by the EHC Chief Executive Officer for a period of three years,
- An open call for volunteers will be sent out to the EHC NMOs. The volunteers can be nominated by any EHC NMO, not just their own. The volunteers shall be selected on the basis of their compliance to the criteria above and on the basis of the quality of their application. The selected candidates will be appointed by the EHC Steering Committee for a period of three years. Once the volunteers are appointed, they may stay on the committee until the end of their term and cannot be removed by the nominating NMO; only by the EHC for just causes.

The EHC Inhibitor Working Group shall appoint a chair with a mandate of one year, who will be responsible for leading the work of the Inhibitor Working Group. (The Chair of the working group shall meet with the EHC Steering Committee once a year to report on the Committee's activities.)

The quorum of the meeting shall be achieved if more than half of the committee members are present. If the chair is not available for the meeting, the IWG can meet nevertheless by selecting an ad-hoc chair for that meeting. However, each meeting does require the presence of at least one EHC SC or MAG member.

If any member of the Inhibitor Working Group shall resign during his/her mandate, the EHC will open call for candidatures in the two months following the resignation to fill the position with an equal candidate for the period until the end of the current term of the IWG.