

EUROPEAN RARE & INHIBITOR NETWORK (ERIN) COMMITTEE

TERMS OF REFERENCE

Role

The ERIN Committee will be responsible for developing, approving and helping to implement the content and the programme of the European Rare & Inhibitor Network (ERIN) in accordance with the project description provided by the EHC. The members of the committee will also be in charge of promoting the ERIN 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 ERIN Committee shall attend and actively participate in:

- Conference calls relevant to the planning and implementation of the activities of the ERIN;
- A face-to-face planning meeting of the ERIN Committee at least once per year;
- Discussion groups within the on-line community;
- EHC events related to extremely rare bleeding disorders/inhibitors.

Members of the Committee may be requested to individually or collectively attend the following events to provide input on the ERIN and exchange experiences:

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

Composition

The ERIN Committee shall be composed of no more than 10 persons:

EHC structures:

- One (1) EHC Steering Committee member,
- One (1) EHC Staff member,

Volunteers:

- Two to three (2-3) persons with extremely rare bleeding disorders of different ages, genders and backgrounds,
- One to two (1-2) persons with haemophilia B with inhibitors or parents of children with haemophilia B with inhibitors,
- One (1) person with haemophilia A with inhibitor or a parent of children with haemophilia A with inhibitors,
- One to two (1-2) multidisciplinary care professionals, e.g. haematologist, physiotherapist, psychosocial specialist, nurse, dental care specialist.

Eligibility

The volunteers shall:

- Be members or have a 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 Rare & Inhibitor Network,
- Commit to dedicate enough time to fulfil the activities carried out by the ERIN Committee.

Selection process and mandate:

The ERIN Committee members shall be selected as follows:

- EHC Steering Committee Member shall be appointed by the EHC Steering Committee for a period of three years,
- EHC staff member 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 ERIN Committee shall appoint a chair with a mandate of one year, who will be responsible for leading the work of the Committee. (The Chair of the Committee shall meet with the EHC Steering Committee once a year to report on the Committee's activities.)

If any member of the ERIN Committee 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 ERIN Committee.

If any member of the ERIN Committee does not attend three consecutive meetings without prior notice and a reasonable explanation, the Committee shall have the discretion to remove his/her membership.