

**STATUTES OF THE EUROPEAN HAEMOPHILIA CONSORTIUM,
INTERNATIONAL NON-PROFIT ORGANISATION (EHC AISBL)**

Last amended October 2021

TITLE I – NAME, HEADQUARTERS, MISSION

Article 1 – Name

The European Haemophilia Consortium, abbreviated EHC, hereafter referred to as « the Organisation», has been established as an international non-profit organisation.

This Organisation is subject to the Belgian Law of June 27, 1921 on international non-profit organisations (AISBL) and all subsequent amendments.

The Organisation has been established on a permanent basis.

Article 2 – Headquarters

The headquarters of the Organisation are located at rue de l'Industrie 10, 1000 Brussels – Belgium, in the judicial borough of Brussels-Halle-Vilvoorde. The headquarters may be relocated anywhere within Belgium by a decision of the Steering Committee duly elected by the General Assembly, published in the annexes of the Belgian Official Journal ('Moniteur Belge') within one month of the decision being taken.

Article 3 – Consortium of European haemophilia organisations

The international non-profit organisation EHC is a consortium of European haemophilia organisations, hereafter referred to as NMOs (National Member Organisations), which advocates on issues relating to haemophilia and other congenital bleeding disorders, promotes training, discussions and consultations, and disseminates information about the conditions.

The Organisation may, upon consultation, represent its members and intervene on their behalf in relation to the well-being of people with haemophilia and other bleeding disorders, and do so for all NMOs as or for a limited number of NMOs.

Article 4 – Objectives

The Organisation has the following objectives:

- Upon request, provide assistance to any NMO to solve issues affecting people with haemophilia;

- Promote the development of NMOs and their cooperation with each other through the exchange of information and collaboration on common initiatives;
- Draft and adopt common positions and actions for tackling problems that affect most European NMOs and represent these, upon request, vis-à-vis international governmental or non-governmental organisations, primarily in relation to the well-being of people with haemophilia;
- Agree on and take collective actions on important issues, including through other associations;
- Promote research and development on quality comprehensive haemophilia care;
- Carry out any action directly or indirectly related to its objectives. The Organisation can support and contribute to any activity in line with its mission.

TITLE II – MEMBERS

Article 5 – Membership

1. The Organisation’s members will be European NMOs, based on the region of Europe as defined by the World Health Organisation (WHO).
2. Only one organisation per country may be designated as that country’s National Member of the Organisation (NMO) and should be legally established in compliance with the laws and customs of their country.
3. To apply for membership, the NMO should:
 - a) Demonstrate democratic governance, procedures and internal processes of electing representative members,
 - b) Have and expect to share their statutes or internal rules of procedure,
 - c) Expect to publicly report income and expenditures and comply with national financial regulations,
 - d) Provide demonstrable patient services based on the needs of all patients,
 - e) Advocate on issues related to bleeding disorders in the best interest of all patients,
 - f) Work strategically with external stakeholders in the best interest of all patients.
4. NMOs shall pay an annual membership fee, determined by the General Assembly of the Organisation.

5. NMOs have the right to vote in the Organisation on matters presented to the General Assembly.
6. NMOs are eligible to nominate individuals to participate the structures of the Organisation.
7. NMOs have the right to participate or be included in relevant Organisation events and programmes as per the objectives of the Organisation (see Articles 3 and 4).

Article 6 – Membership application procedure

All membership applications shall be subject to a decision by the General Assembly, upon recommendation by the Steering Committee as per the procedure established in the Internal Rules of the Organisation

Article 7 – Removal, Exclusion

Any member may remove itself from the Organisation with immediate effect by notifying the President in writing and pending ratification by the General Assembly.

A violation of article 5, numbers 1 to 4, by an NMO could lead to the exclusion of the NMO from the Organisation or a suspension of some NMO rights, as stated in article 5, numbers 5 to 7.

The competence for excluding and suspending an NMO belongs to the General Assembly of the Organisation, upon reasoned proposal of the Steering Committee.

The NMO has the right to be heard by the Steering Committee prior to a proposal of exclusion or suspension being presented to the General Assembly, and also has a right to be heard during the General Assembly, before a final decision is made.

The General Assembly deliberation on exclusion and suspension follows the voting rules stated in articles 10, 11 and 12.

An NMO that for whichever reason ceases to be a member of the Organisation shall have no claim on financial compensation or on the Organisation's assets. Membership fees shall remain due until the end of the year.

TITLE III – ORGANISATIONAL STRUCTURES, SECRETARIAT

Article 8 –

Par. 1

The highest decision-making body of the consortium is the General Assembly of NMOs which meets annually. Between General assemblies, the organisation is overseen by a Steering Committee comprised of minimum six and maximum eight members, including a President, a Vice-President Finance and four elected representatives from eligible European NMOs, and if necessary up to two co-opted members. The

management of the organisation staff and the day to day running of the organisation is the responsibility of the CEO. The CEO is appointed by the Steering Committee and reports to the Steering Committee via the President.

Par. 2

In the event that the President is not available, the Steering Committee shall be chaired by the Vice-President Finance or an alternative member of the Steering Committee selected by those present at the meeting.

Par. 3

Steering Committee elections shall be held during General Assemblies.

Par. 4

Members of the Steering Committee are elected for a term of three years; the President and the Vice-President Finance are elected for a term of four years.

Par. 5

Elected-members of the Steering Committee have the power to choose and appoint two co-opted members from European NMOs. The Steering Committee may also make co-options to ensure the replacement of someone who stepped down or passed away before his/her end of term. A co-opted member from a European NMO filling a vacant seat shall retain the seat until the next elections.

Par. 6

The CEO manages the Organisation; he/she prepares the budgets, guidelines and position papers to be reviewed by the President and Vice-President Finance and approved by the Steering Committee. The CEO with approval from the President and the Vice-President Finance takes the necessary steps to receive public and private funding as well as donations. The President drafts the Internal Rules for approval by the General Assembly.

Par. 7

The budget shall be presented to the General Assembly by the Vice-President Finance on behalf of the Steering Committee.

Par. 8

All NMOs in the Organisation have the right to nominate individuals for the Steering Committee. During the election, each NMO shall have one vote. In an election year, a call for nominations shall be sent to all NMOs by the secretariat at least eight weeks prior to the annual General Assembly.

Par. 9

Nomination forms must be returned by the deadline communicate in the call for nominations; each candidate must submit a letter of motivation of approximately 300 words outlining his/her expertise and reasons for wanting to join the Steering Committee. Information about the candidates shall be provided by NMOs at least four weeks prior to the annual General Assembly. The vote shall take place and be announced at the General Assembly.

Par. 10

The Steering Committee shall act on behalf of all NMOs, including without prior consent from each individual NMO, in the event that it is necessary to act within a limited timeframe and/or when the action is in line with guidelines drafted and accepted during an EHC General Assembly or through written consultations. The Steering Committee must inform NMOs in a timely manner when it takes positions on issues not previously discussed with them.

Par. 11

The Steering Committee meets at least three times per year, convened by the President, with indication of the date, place and agenda. Meetings may be held in person or by conference call.

Article 9 – Annual General Assembly

The Annual General Assembly is convened by the President with indication of the date, place and agenda, and generally coincides with the annual EHC Conference. The date is announced at least three months in advance.

The General Assembly is comprised of European NMOs (in conformity with article 4).

The General Assembly is the highest authority in the Organisation; it shall be vested with all the powers necessary to carry out the mission of the Organisation in conformity with articles three and eight.

These powers include:

- Approving budgets and audited accounts;
- Setting the annual membership fee;
- Approving the annual work plan upon the recommendation of the Steering Committee;
- Approving the annual report;
- Approving and modifying the Internal Rules of the Organisation;
- Monitoring the activities of the Steering Committee;
- Modifying the Statutes;
- Disbanding the Organisation;

<ul style="list-style-type: none"> • Approving resolutions; • Selecting the country/city for future General Assemblies.
Article 10 – Extraordinary General Assembly
An extraordinary General Assembly may be convened by the President or by written request either by two thirds of the Steering Committee membership or by 51% of European NMOs. Such a General Assembly shall be composed, take place, and act like an ordinary General Assembly.
Article 11 – Quorum, Votes
<p>The General Assembly shall deliberate based on a simple majority of delegates present or represented, without accounting for abstentions. Each NMO shall have the right to one vote.</p> <p>An exception is made for resolutions regarding the modification of the Statutes or the disbandment of the Organisation, which require a two-thirds majority of delegates present or represented, without accounting for abstentions.</p>
Article 12 – Proxies – Procedures
<p>Votes by proxy are permitted. However, delegates are limited to two proxy votes.</p> <p>The procedures governing General Assembly deliberations and decision-making shall be set by the Internal Rules.</p> <p>The General Assembly shall be chaired by the President or a Chairperson invited by the President with approval from the Steering Committee.</p>
Article 13 – Relations with the WFH
The Organisation and the World Federation of Hemophilia (WFH) shall engage and collaborate with each other, as relevant, and as guided by a joint memorandum of understanding.
Article 14 –
Each NMO shall designate a representative to act as the contact person for the Organisation. It is the obligation of the NMO to inform the secretariat of any changes in contact person or contact details.
Article 15 – Secretariat
The secretariat is located at Organisation’s headquarters. Decisions on this matter shall be taken by NMOs at the General Assembly.
TITLE IV – REPRESENTATION

<p>Article 16 – Representation vis-à-vis third parties</p> <p>The Organisation shall be officially represented vis-à-vis third parties and in all actions by the President or by members of the Steering Committee or the CEO, as duly authorised by the President.</p> <p>Any legal proceedings, whether as plaintiffs or as defendants, shall be commenced by the Steering Committee, represented by the President or by the Vice-President Finance.</p> <p>For day-to-day management, the Organisation shall be officially represented vis-à-vis third parties by the CEO.</p> <p>None of the above-mentioned individuals need to confirm their authority vis-à-vis third parties.</p> <p>In addition, the Organisation shall be officially represented within the framework of its mandate by a proxy-holder duly authorised by the CEO, Steering Committee or the President.</p>
<p>TITLE V – FISCAL YEAR</p>
<p>Article 17 –</p> <p>The fiscal year of the Organisation shall run from January 1st to December 31st of each year.</p> <p>A financial report must be transmitted to members within three months of closing.</p>
<p>Article 18 – Disbandment and liquidation</p> <p>In case of the Organisation’s voluntary disbandment, after the payment of debts and settlement of charges, the General Assembly, which will have determined the disbandment, shall also determine the beneficiary of the disbanded Organisation’s assets and give these to an organisation whose mission aligns as closely as possible to that of the disbanded Organisation. The General Assembly shall choose this institution.</p> <p>If the General Assembly takes no decision regarding the beneficiary of assets within six months of the decision to disband the Organisation, the allocation of these assets shall be determined, upon the request of an NMO, by the Court (‘Tribunal de première Instance’) presiding over the headquarters.</p>
<p>TITLE VI – FINAL PROVISIONS</p>
<p>Article 19 –</p> <p>Anything not stipulated under these Statutes shall fall under the provision of Title III of the Belgian Law of June 27, 1921 on non-profit organisations, international non-profit organisations and foundations.</p>