



The European Porphyrria Network

CONSTITUTION (Statutes and bylaws)

Statutes

§ 1: Name

The name of the Association is the "European Porphyrria Network" (EPNET). Registered April 1, 2017.

Its registered office is in Bergen, Norway. EPNET is a non-profit learned association (or scientific association)

The term of the Association is unlimited. It may be dissolved at any time.

The English language shall be the working language of the Association.

§ 2: Scope

EPNET will promote fundamental and clinical research in the field of porphyrias, improve knowledge of the porphyrias and facilitate best practice in their treatment and diagnosis by accommodating and interconnecting expert activities across Europe in the service of porphyria patients:

- Establishing common approaches to optimize diagnostics, prevention, management and treatment of porphyria patients
- Developing and implementing harmonized laboratory, diagnostic and treatment guidelines,
- Maintaining the EPNET website including publishing EPNET news and practice guidelines
- Supporting the EPNET scheme for External Quality Assurance (EQA) of porphyria related activities.
- Supporting The Drug database for the Acute Porphyrrias
- Develop training and education opportunities to ensure continued expert skills in the field of porphyrias, also in European countries where this is lacking
- Supporting the European Porphyrria Registry (EPR)
- Organizing meetings with scientific or practical themes for members and other interested parties
- Stimulating, developing and organising cross-border research and innovative treatments
- Issuing scientific publications, including books.
- Representing porphyria activities within other organizations, networks such as MetabERN, etc.

§ 3: Legal person

The association is self-owned with limited liability for debt. Individual members have no personal liability for debt.

§ 4: **Members**

EPNET has four types of membership: Full member, Associate member, Honorary member and Corporate member.

Full member:

A full member can only be a Centre for Porphyrin Expertise established in Europe (as defined by the WHO) that renders clinical and laboratory services to porphyria patients, that is free of political or other influences and that meets the following requirements:

- Provide analysis of urinary ALA, PBG (quantitative), total porphyrins and fractionation of porphyrins, faecal total porphyrins and fractionation with separation of coproporphyrin I/III isomers, separation of free and zinc protoporphyrin in erythrocytes, and plasma fluorescence scanning
- Give detailed interpretation of laboratory results with expert comments and provides expert clinical advice on management of all porphyria patients according to EPNET guidelines
- Participate in the EPNET EQA scheme which addresses the total testing process for all porphyria-related metabolites
- Interact with patient organization(s)
- Provide public reports of activity
- Provide education and training

Associate member:

- Impartial non-European Centres of Porphyrin Expertise which provide clinical and laboratory service to porphyria patients
- European Centres of Porphyrin Expertise that do not yet fulfill the criteria for being an EPNET Centre of Expertise
- European porphyria patient organizations
- Health care professionals and scientists with an interest in porphyria

Honorary member:

- Individuals nominated by EPNET Executive Board (EB) in recognition of their contribution to the field of porphyrias

Corporate member:

- Commercial companies with an interest in the field of porphyria

Application of membership

An applicant wishing to become a member of EPNET shall send an application in writing to the Executive Board (EB), who then forwards it to the next General Meeting. The General Meeting's decision is final and does not need to be justified.

Termination of membership

Termination of membership can only be done in written form, either by letter or e-mail, to the secretary of the EB. If a member does not fulfill its duty to pay the annual membership fee within the required timescales, the EB has authority to cancel the member's membership. Termination of membership will be confirmed in writing by the EB.

§ 5: **Voting rights and eligibility**

Only full members have voting rights in the General meeting (GM). Only individuals employed in an organisation that is a full member can be elected to the Executive Board

§ 6: **Finance and Membership Fee**

The income of EPNET is derived from the annual membership fees, income from organized meetings, including the International Conference of Porphyrins and Porphyrias (ICPP) meetings, donations, gifts and

bequests to EPNET. All members, apart from honorary members, pay an annual membership fee. The yearly fee is approved at the General Meeting (GM). The annual membership fee must be paid within the calendar year January to December.

§ 7: Honorarium

The members in the Executive Board shall not be economically compensated for their work.

§ 8: The General Meeting (GM)

The General Meeting (GM) is the organ of general management of the EPNET and determines its general policy. The GM has the powers expressly foreseen by the law or the present Articles of EPNET. The GM shall have sole competence to:

- Amend the Articles of EPNET;
- Appoint and dismiss the Executive Board (EB) members;
- Where necessary, appoint and dismiss the auditors and set their remuneration, if any;
- Grant discharge to the EB members;
- Approve the budget and accounts;
- Voluntarily dissolve the association;
- Admit or expel members

The General Meeting is composed of all members of EPNET and is chaired by the President. In his or her absence the chair shall be held by the longest serving member of the Executive Board who is present at the GM. If more than one of the present EB members have the same serving time in the EB, the chair shall be held by the one having seniority over the other.

The GM should meet “physically” as a minimum every second year. GM receives the report of the EB on EPNET’s activities during the past two years. It approves EPNET’s accounts submitted to the GM. It deals with the elections and approves the budget.

The EB prepares the agenda for the GM and sends to all members notices by ordinary post or by e-mail addressed to each member at least 20 days in advance. The agenda is included in the notices and the GM may deliberate on the matters on the agenda only.

Members can propose topics for the agenda. If the EB does not want to have the topic on the agenda, the topic has to be on the agenda if signed by one fifth of full members.

If a proposal of amendment to the Articles of EPNET or a proposal to dissolve EPNET is on the agenda, notices have to be sent by registered letter and/or email or fax (in the last two cases, with acknowledgment of receipt) to all the members.

§ 9: Voting procedure

Only Full Members have voting rights at the General Meeting, and each full member has one vote.

The GM elects the Executive Board (EB) from the nominated candidates, namely a President, a Secretary, a Treasurer and two to four full members through a simple majority of votes amongst the full members. EB members are elected for a two years period of office and may be re-elected for an additional two periods. If an EB member resigns before his or her term expires, the EB can designate an interim member until the next GM and election.

Each Full member shall designate a person who exercises his/her rights and obligations within EPNET on behalf of the relevant member.

If a Full Member cannot take part in the GM, she or he may give a proxy to be represented and vote. Any proxy must be given in writing and sent to the EB. The proxy may be given to the President of the General Meeting or to any Full Member. Except the President of the General Meeting, no one may hold more than one proxy. The candidate to a position of membership of the Executive Board may not be proxyholder.

European patient organisations that are associate members of EPNET can elect one representative to the EB but will not have voting rights within the EB.

Corporate members have no voting rights but are entitled to a meeting with the EB every year.

The General Meeting may use electronic voting.

§ 10: General Meeting tasks

- General meetings (GM) shall compile an annual report of achievements and yearly financial accounting. The GM determines the annual fee for full members, associate members and corporate members. The Treasurer must submit the annual accounts to two Honorary Auditors. The Honorary Auditors shall be full members of EPNET (but not members of the EB), elected for two years by the General Meeting. The Honorary Auditors advise the General Meeting of the accuracy of the income and expenditure account and the balance sheet of EPNET. The GM must approve the annual accounts reported by the Treasurer.
- Remit incoming motions.
- Elect members for the Executive Board.
- The decisions of the General Meeting shall be recorded in minutes, signed by the Chairman of the General Meeting and the Secretary and forwarded to all full members by e-mail.

§ 11: Extraordinary General Meetings

The Executive Board has the power to convene an extraordinary General Meeting at any time. An extraordinary General Meeting should be convened at the request of at least one fifth of the full members. The meeting will be held on the date and at the time and place indicated in the notice and all members must be invited.

§ 12: Remits of the Executive Board (EB)

The Executive Board should meet as a minimum every year with an option of more frequent meetings and/or telephone conferences.

The remits of the EB are:

- To promote and facilitate porphyria-related work amongst its members including establishing working groups and initiating projects.
- To organize EPNET meetings, including the biannual EPNET International Porphyrins and Porphyrins (ICPP) meetings. The scientific committee for such meetings will be appointed in collaboration with local organizers and will include international representatives. Meetings may be held outside Europe.
- To facilitate further development of the European Porphyria Registry (EPR).
- To organize General Meetings.
- To maintain a register of existing members.
- To inform the membership of its activities and provide an annual report.
- To maintain the EPNET budget and provide financial transparency to the members.
- To interact with and support European porphyria patient organizations

§ 13: Amendment of the Statutes

The statutes can only be amended by a resolution of the GM

Revised statutes must be submitted to and approved by at least 50% of the members. The EB must inform its members about the proposed revised statutes along with the invitation for the GM.

§ 14: Dissolution of EPNET

Dissolution of EPNET can only be decided in a General Meeting. In the event of suspension EPNET's assets will be employed to realize the same goals as set out in these statutes.

Bylaws

Note 1.

GUIDELINE FOR EPNET WORKING GROUPS

EPNET may establish working groups to address scientific or educational issues.

Guidelines

1. The working group should be established by the EB.
2. The working group must clearly define the area of interest, their aims and objectives.
3. Members of a working group must be a member of EPNET. All grades of EPNET membership are eligible to register as a member of a working group.
4. The working group must be lead by a chairperson. The chair is appointed by the EB for a period of two years. The mandate is renewable for a maximum of two further periods. Working group members are appointed by the chair and endorsed by the EB.
5. The working group should meet or have a video/phone conference at least once a year.
 - a. At this meeting the activities and progress over the last year(s) are discussed.
 - b. At this meeting a work plan for the next year should be established.
6. The recommended output must be in the form of a scientific publication and/or a report to the members of the association.
7. Activities and the work plan must be reported to and approved by the EB
8. All activities / reports must be published on the EPNET website.
9. Individual members of working groups must provide statements on potential conflict of interest (e.g. consultancies for diagnostic or drug commercial companies in the field of the porphyria).

Note 2.

<h2 style="text-align: center;">VOTING PROCEDURE FOR EB MEMBERS</h2>
--

Procedure

1. The EB calls for candidate board members from its full members.
2. The EB prepares a list of potential candidates based on the proposals received.
3. The list of candidates is distributed to the full members of EPNET.
4. The voting procedure can be done by distributing a voting form, electronic ballot or at a “physical” General meeting
5. Unless there is more than one nominee for any EB position, voting will be by acclamation.
6. If there is more than one nominee for any EB position voting will be by secret ballot at the General Meeting. Each position will be voted upon independently of the other, this means that in voting representatives must indicate only one preference on the voting slip. After voting for the first Member, the remaining candidates will participate in a further ballot for the other positions as Member.
7. Elected candidates must receive at least 50% of the votes cast. If no candidate receives more than 50% of the vote on the first ballot, the candidate receiving the smallest number of votes is eliminated and the voting is repeated.
8. This process continues until one candidate has received more than 50% of the votes cast. In the event of a tie between two candidates, the election is repeated between those candidates. Should this lead to a further tie, then the President has a casting vote.
9. The votes are counted by two independent members who are appointed at the General Meeting. The results of the election are presented immediately at the General Meeting.