



European Society for Phenylketonuria
and Allied Disorders treated as Phenylketonuria
(E.S.PKU)

Statutes

January 1997, revised January 2000



Statutes

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I Name, Headquarter, Duration

Art. 1: Name

The name of the society is “European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria”, abbreviated and called thereafter “E.S.PKU”.

Art. 2: Headquarter

The E.S.PKU headquarter is registered as follows:

Woestijne 16
B-9880 Aalter/Belgium

It may only be changed by the resolution of the General Meeting.

Art. 3: Duration

The duration of E.S.PKU is unlimited. It can be dissolved at any time in accordance with Art. 13 of the statutes.

II Aims and Objectives

Art. 4: Aims and Objectives

The E.S.PKU has been established for the aims as follows:

- a) To promote the educational and social welfare of persons affected of phenylketonurais (abbreviated PKU) and allied disorders treated as phenylketonuria;
- b) To stimulate scientific and medical research in PKU;

it may explore all activities that can promote the aims of E.S.PKU such as:

- to give and to distribute informations and to advise its members;
- to organize meetings;
- to edit periodicals;
- to promote the establishment of national societies;
- to undertake projects and to cooperate in undertakings that promote the aims of E.S.PKU;
- to undertake activities in support of the aims of its members and the interest of the society as a whole.

The society may explore economic activities and conditions to use the profits for the promotion of the aims of E.S.PKU.

III Members

Art. 5: Number of Members

The number of members is unlimited. The founders of E.s.PKU are the persons as mentioned in the enclosure “Declaration of Membership”.

Art. 6: Categories of Members

The E.S.PKU is composed of the following categories of members:

- a) Legal Members
- b) Associate Members
- c) Honorary Members
- d) Partners

Art. 6a) Legal Members

Legal members are national or regional organisations. Their aims must correspond to the aims of E.S.PKU.

National organizations, as far as they exist, should have priority over regional organizations.

Each Legal Member can be represented by two persons.

Each Legal Member has one vote.

One representative of any Legal Member may vote by proxy of the other representative.

Legal Members must be in good order.

The membership fee must be paid in full before the 5th month of the current year.

Art. 6b) Associate Members

Associate Members are those organizations, which do not pay a membership fee.

Associate Membership shall be ratified by the General Meeting by simple majority acc. To Art. 7.

They maintain contacts through the Executive Bureau and will be informed about the work of E.S.PKU at any time.

Associate Members have no right to vote.

They may, however, attend the General Meeting as observer.

In exceptional cases, Associate Members may apply for subsidy by the social fund, to be recognized as Legal Members.

Associate Membership shall not exceed two years beginning with the resolution of the General Meeting ratifying the Associate Membership. In exceptional cases prolongation of the Associate Membership may be granted by resolution of the General Meeting.

Art. 6c) Honorary Members

Honorary members are individuals or organizations nominated by the General Meeting. They have no right to vote.

Art. 6d) Partners

Partners are institutions with a special interest in metabolic disorders, for example universities, hospitals, manufacturers and distributors.

They will maintain contacts through the Executive Bureau on international issues.

Partners do not attend the General Meeting.

Art. 7: New Members

Any decision regarding membership must be ratified by the General Meeting by simple majority.

Art. 8: Discharge or Exclusion of Members

The discharge or exclusion of a member will be forfeited by resignation, dissolution, non payment of fee, or exclusion of serious reasons in accordance with the Belgian Law of June 27th, 1921, Art. 21, which governs non-profit organizations.

In these cases, the presence of 50% of Legal Members is necessary. The decisions need a majority of two third of present Legal Members to confirm it under Belgian Law as mentioned above.

The discharged or excluded members and their successors take no longer part in the matters of E.S.PKU.

They have no right regarding the funds of E.S.PKU or any contributions made for the society.

Art. 9: Membership Fee

The membership fee will be proposed each year by the Executive Bureau.

It may not exceed 25.000 BFr.

The annual membership fee must be approved by the General Meeting.

(Remark: The actual membership fee is 400 € plus 20 € bank charges per year since the year 2005).

Art. 10: Responsibilities

Individual members are in no way responsible for the actions and decisions undertaken by E.S.PKU.

IV Structure

Art. 11: Structure

The structure of E.S.PKU is as follows:

- a) The General Meeting
- b) The Executive Bureau
- c) The Scientific Advisory Committee

Their functions and way of working are described in the E.S.PKU Handbook.

This Handbook provides in detail the information about the procedures and responsibilities of all aspects of E.S.PKU and its operations.

It can be changed by a simple majority of the present Legal Members at the General Meeting. Changes should be proposed by the Executive Bureau.

Art. 11a) The General Meeting

The General Meeting is composed of:

- All Legal Members represented by two persons maximum, each Legal Member having one vote.
- One representative of the Scientific Advisory Committee with one vote.

The General Meeting reflects on the direction and activity of E.S.PKU and is competent for:

- Approval of the internal rules of the society;
- Approval of the E.s.PKU budgets and accounts;
- Amendments of the Statutes;
- Voluntary dissolution of the E.S.PKU;
- Exclusion of members;
- Election of the President;
- Election and dismissal of the Executive Bureau Members.

All decisions shall be adopted by a simple majority of the number of members present, other than:

- Changes of Statutes
- Exclusion of Members
- Voluntary dissolution

In these cases, the presence of 50% of Legal Members is necessary. The decisions need a majority of 2/3 to confirm it under Belgian Law as mentioned above.

Once a year, a General Meeting will be held.

The written invitation will be mailed at least one month prior to the date of the General Meeting and will contain:

- Venue / place
- Agenda
- Discharge of the Officers of the Executive Bureau
- Request for Candidates for the Executive Bureau

Of each meeting, a report will be performed and signed by the President and an Officer of the Executive Bureau.

Art. 11b) The Extra-ordinary General Meeting

The extra-ordinary General Meeting will be held whenever circumstances demand such a meeting and/or when 1/3 of the Legal Members ask for a meeting to take place.

Communications are valid when signed by the President or by two Officers or 1/5 of the members.

The communication for an extra-ordinary General Meeting will be mailed by post at least two weeks prior to the date of the meeting. It will state venue, day, hour and agenda for the meeting. This will be determined by the Executive Bureau, however, 1/20 of the Legal Members have the right to set items on the agenda.

The General Meeting or an Extra-ordinary General Meeting is presided over by the President of the Executive Bureau or in his absence of the most senior member. The meeting can refuse to accept the President and can vote this by simple majority.

Art. 11c) The Executive Bureau

The Executive Bureau is composed of a minimum of

- A President
- A Vice-President
- A Secretary
- A Treasurer

They are elected from the Legal Members Meeting.

- A Member of the Scientific Advisory Committee
- Additional members (up to a maximum of four) can be appointed, if required for specific projects, from the General Meeting or from outside.
- The Executive Bureau can employ an assistance if approved by the General Meeting.

The functions and purposes of the Executive Bureau are:

To execute acts of management: A schedule of duties for which the individual officers are responsible, is included in the E.S.PKU Handbook.

The President and the Officers are elected for three years and can be renominated.

Art. 11d) Scientific Advisory Committee

Each Legal Member has the right to delegate two persons in the E.S.PKU Scientific Advisory Committee, one prental or adult PKU representative and one professional representative.

Each Legal Member has one vote.

The Scientific Advisory Committee has one representative in the Executive Bureau and one in the General Meeting.



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Associate Members may attend the meetings of the Scientific Advisory Committee as observers without voting right.

The purpose, function and organization of the Scientific Advisory Committee are described in the E.S.PKU Handbook.

V General Terms

Art. 12: Financial Regulations:

The financial year runs from July 1st, to June 30th.

Accounts and budgets are prepared by the Executive Bureau and presented to the General Meeting for approval.

The General Meeting nominates an auditor from its Legal Members, who is responsible to verify the accounts and to report to the General Meeting.

The Auditor is eligible nominated for two years.

Art. 14: Dissolution of E.S.PKU

Independent of the reasons for dissolution, the profits of E.S.PKU have only to be used for a social purpose whis is consistend with the aims of the society.

The General Meeting must pror to dissolution satisfy itself that this purpose has been fulfilled.

Art. 15: Any matters not covered by the statutes

Any matter, not covered by the E.s.PKU Statutes, will be regulated according to the Belgian Law of June 27th, 1921.

In this way, with unanimity of votes at the Foundation Meeting in Aalter, October 4th, 1987, and there ratified on May 11th, 1991, and with 17 of 18 votes changed on Nvember 1st, 1996 at the Legal Members Meeting in Unterägeri / Switzerland, the E.s.PKU Statutes are accepted.

Explanation to Art. 5:

Declaration of Membership:

Memorandum of Foundation on October 4th, 1987, in Aalter, Belgium

Founding Members:

- K. Dodsworth, England
- J.M. Criem, Belgium
- R. Rohr, Germany



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Editorial Remarks:

(October 2010)

Due to changings in Belgian Law and to the adoption of current working structures of E.S.PKU, some parts of these Statutes ar no longer valid. New Statutes are actually prepared to be presented to an upcoming General Meeting.