



Statutes of the "European primary hyperoxaluria patient advocacy group" (PH Europe)

§ 1 Name and seat of the association

The name of the association is: European primary hyperoxaluria patient advocacy group (PH Europe).

The seat of the association is Berlin, Germany.

It is registered in the register of associations of the district court of Berlin under the number -----.

The association is completely independent.

The fiscal year is the calendar year.

§ 2 Purpose of the association

PH-Europe pursues exclusively and directly non-profit purposes in the sense of the section "tax-privileged purposes" of the tax code. The purpose of PH-Europe is the promotion of science and research and the promotion of public and professional education (§ 52 Abs. 2 Nr. 1 AO), e.g. by financing research projects (within the permissible transfer of funds according to § 58 AO) in the field of primary hyperoxaluria and the development of new treatment options. The association will establish its own guidelines for the allocation of funds.

Furthermore, a promotion of charitable purposes in the sense of § 53 AO is to be made possible. This means, for example, the support of patients with any form of primary hyperoxaluria as well as their relatives anywhere in Europe in the striving for adequate

diagnostics and effective therapy. Another means to fulfill the purpose is public relations (posters, flyers, appearances at trade fairs and congresses, apps, videos) to increase awareness of this disease.

§ 3 Selflessness

PH-Europe operates selflessly; it does not primarily pursue its own economic purposes.

§ 4 Means

The funds of PH-Europe may only be used for the statutory purposes. Members shall not receive any benefits from the funds of the association.

§ 5 Benefits

No person may be favored by expenditures, which are foreign to the purpose of PH-Europe, or by disproportionately high remunerations.

§ 6 Membership

Ordinary membership: Natural and legal persons and other associations, which are willing and able to promote the aims of PH-Europe in the sense of these statutes, can become ordinary members. The Board of Directors decides on the written application for ordinary membership by resolution. Membership in PH-Europe is subject to membership fees. Details are regulated by the membership fee regulations.

Supporting Membership/Cooperative Memberships: Sponsoring members of PH-Europe are natural or legal persons who support the goals and tasks financially and/or materially. They pay a membership fee, but have no voting rights and no active or passive election rights. Legal entities may become cooperative members. The amount of the membership fee is determined on a case-by-case basis by the Board.

Honorary membership: The Board may propose honorary members who have rendered outstanding services in supporting or realizing the goals of PH-Europe. The General Assembly decides on the application. Honorary membership is free of charge.

§ 7 Termination of membership

The membership ends by:

Death of a member

resignation

exclusion

dissolution of PH-Europe

in case of legal entities with termination of business activity

Resignation is permitted with a notice period of 6 months to the end of the year. The resignation must be declared in writing to the Board of Directors. If the resignation is not made in due time, the membership will be extended until the end of the next following business year. Membership, rights and obligations thus continue during the period of notice.

A member may be expelled by resolution of the Board if he/she has acted in a manner contrary to the interests of PH-Europe. Before the resolution is passed, the member must be given the opportunity to comment.

§ 8 Bodies

The organs of PH-Europe are the General Assembly and the Executive Board.

§ 9 General Meeting

The tasks of the General Assembly are:

To establish the general guidelines,

to receive the activity reports and the annual financial statement,

to decide on the discharge of the Board of Directors,

to elect new members of the board, if necessary to appoint them

to decide on the admission of honorary members

to adopt the budget

to decide on the scale of contributions,

to decide on amendments to the statutes
to decide on the dissolution.

§ 10 Convocation of the general meeting; passing of resolutions

The 1st chairperson invites the general meeting once a year. It must also be convened if the majority of the board or at least 1/3 of the members demand it.

The members must be invited in writing at least four weeks before the meeting, enclosing the agenda set by the Board. The period begins two days after the invitation letter has been sent. In urgent cases, the invitation period may be reduced to one week.

The general meeting decides with a simple majority of votes, as far as these statutes do not provide otherwise. In the event that a member is prevented from attending, another member may be authorized in writing to exercise the voting right; the authorization must be issued separately for each general meeting. However, a member may not represent more than three third-party votes.

The general meeting shall be chaired by the 1st chairperson, or if he/she is prevented from doing so, by his/her deputy, the 2nd chairperson. If both board members are prevented, the general meeting elects the chairman of the meeting from among the members present.

The resolutions are to be recorded in the minutes of the meeting. The minutes shall be signed by the chairman of the meeting and the secretary. Objections to the correctness of the minutes must be raised with the chairman within 14 days of receipt of the minutes.

§ 11 The Executive Board

The board of directors is honorary. The board consists of the:

1st chairman/chairwoman

2nd chairman/chairwoman

treasurer

secretary

up to 4 assessors

The members of the board are elected by the general meeting with simple majority for a term of two years. They remain in office until a new election is held. If a member of the board resigns during his/her term of office, the board shall elect a substitute member for the remaining term of office of the resigning member.

The Executive Board shall be elected by secret ballot in a number to be determined in advance in accordance with § 9 para. 1. If all those entitled to vote are in favor, an open election may take place. The ordinary members have the right to propose candidates.

The elected elect among themselves the positions mentioned in § 9 para.

The 1st chairperson is authorized to represent the interests alone, the other board members can only represent the interests together with one other board member each.

This does not apply to the following transactions:

- Contracts with a term of more than one year

- Employment contracts

- Real estate transactions

- Contracts with a business value of more than 5,000.00 euros

The aforementioned transactions can only be effectively concluded by the Chairperson together with another member of the Executive Board.

The Executive Board is responsible for the affairs of PH-Europe, unless they are assigned to another body by the Articles of Association. In particular, it has the following tasks:

- Preparation of the General Meetings,

- Preparation of the agenda for the General Assembly,

- Convening the General Assembly,

- Execution of the resolutions adopted in the General Assembly,

- preparation of a budget for each fiscal year,

- preparation of an annual report,

- passing resolutions on the admission and exclusion of members.

The Board of Directors may avail itself of the assistance of the Advisory Board in its activities.

Amendments to the Articles of Association required by legal or financial authorities for formal reasons may be made by the Board on its own initiative. This shall only apply if the necessary amendments to the Articles of Association leave no alternative. These amendments shall be communicated to the ordinary members as soon as possible.

§ 12 Passing of Resolutions by the Executive Board

The 1st chairperson invites the board to meetings, which must take place at least twice a year. He/she must also invite it if the majority of the board members request this, stating the subject of the resolution.

The members of the Board shall be invited in writing at least one week before the meeting, enclosing the agenda.

The meeting of the Board of Directors shall be chaired by the 1st Chairperson or, if he/she is prevented from attending, by the 2nd Chairperson.

The Executive Board shall constitute a quorum if all its members have been invited in accordance with the Articles of Association and at least three members of the Executive Board are present. It shall also constitute a quorum if it has been invited for the second time in accordance with the Articles of Association for the same subject matter and it has been pointed out in the invitation that a resolution may be adopted without a sufficient number of members being present. The transfer of voting rights to another member of the Executive Board is not permitted.

The Executive Board shall decide by simple majority. In the event of a tie, the 1st Chairperson shall have the casting vote.

Resolutions passed in writing are valid if they are unanimous. A message written by e-mail is recognized by electronic signature.

The resolutions shall be recorded in minutes of the meeting. The 1st chairperson and the secretary must sign the minutes. Objections to the accuracy of the minutes must be raised with the chairperson within 14 days of receipt of the minutes.

§ 13 Advisory committees, working groups

The board of directors may establish an advisory board, committees and working groups to provide expert advice, to prepare documents, to prepare events and to expand the activities of the association in accordance with the goals of the articles of association

The members of the advisory board are elected by the board of directors. The advisory board elects the chairperson from among its members.

The Advisory Board may also call in experts from outside the interest group to its meetings. The members of the Advisory Board have the right to attend the meetings of the Advisory Board.

Each member of the Advisory Board is elected for two years.

Committees and working groups are formed as needed. The Executive Board may appoint or dismiss their chairpersons.

§ 14 Dissolution of the Association

The dissolution of the Association can only be decided at a General Meeting with the votes of $\frac{2}{3}$ of the members present.

§ 15 Assets

In the event of the dissolution of the Association or the discontinuation of tax-privileged purposes, its assets shall be transferred to the Verein zur Förderung medizinischer und pädagogischer Kommunikation und Information in den neuen Medien e.V., Cologne, which shall use them directly and exclusively for tax-privileged purposes. This association is entered in the register of associations at Cologne Local Court under the registration number VR 17496.