

Constitution ASBL

EUROPEAN GENETIC ALLIANCES' NETWORK (EGAN)

**Association sans but lucratif
1050 Bruxelles, Avenue Louise 287**

**THE YEAR TWO THOUSAND AND FIVE
THE FIRST OF MARCH**

Present:

- The association incorporated under the laws of the Netherlands “Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP)”, Vredeshofstraat 31, 3761 HA Soestdijk, Nederland, hereby represented by M. Cor Oosterwijk, Director ;
- The association incorporated under the laws of Great Britain “Genetic Interest Group (GIG)”, Unit 4d, Leroy House, 436 Essex Road, London N1 3QP, Great Britain hereby represented by M. Alastair Kent, Director;
- The association incorporated under the laws of the Netherlands “HEART EU, De Europese Cholesterol Patiënten Stichting”, Karel Doormanplantsoen 7, 2121 XA, Bennebroek, Nederland, hereby represented by M. Adrianus Cornelis van Bellen, Director;

Asking to draw up the present Statutes of a non profit association, which they declare to constitute between them in accordance with the law of June 27, 1921, as modified by the Law of May, 2, 2002.

Chapter 1 - Name, Registered Office, Term, Objectives

Article 1. Name

The name of the association shall be “European Genetic Alliances’ Network” abbreviated to EGAN hereinafter referred to as “Association”.

Article 2: Registered Office

The Association has its registered office at 287 avenue Louise, 1050 Brussels in the judicial district of Brussels. The Board of Directors is authorized to transfer the registered office to every other place by simple majority.

Article 3. Term – Minimum number of members

The Association is constituted for an unlimited duration. It is composed of a minimum of three members.

Article 4. Purpose

The Alliance aims include:

- working together with other existing European patient alliances and organizations to build a unified and approach to genetic and biotechnological issues from the patient perspective, respecting the fields of interests of partnering and non-partnering organizations;
- public advocacy and influence, articulating a clear, patient focused perspective on human genetic and medical biotechnological issues, including their ethical, legal, psychosocial and cultural implications in the European political, scientific and commercial arena;
- supporting and facilitating individual patient organizations and alliances in their activities for opinion shaping, advocacy and influencing healthcare policies on a national and European level regarding disease specific issues;
- providing a patient platform for opinion making and collective priority setting, communication and pro-active intervention in relevant genetic an biotechnological issues
- presenting the patient perspective related to genetics and biotechnology, in European projects, societies, expert committees, working groups, etc.;

The Association may engage itself in any transaction, which it deems useful and which relates directly, or indirectly to is purposes. It may grant its collaboration to and take an interest in any activity, which is similar to its purposes.

Chapter II – Membership

Article 5. Membership

The members of the Association are non-profit and non-governmental patient organisations constituted under the appropriate legal status in their country of origin. There will be two categories of members :

Article 6. Categories of Membership

There are two types of memberships:

Ordinary members: which may be any patient organisation that has a specific interest in genetics and biotechnology and that represents either more than one specific condition on a national basis, or one specific condition on a multi-country level within Europe.

Associate members: which may be any patient organisation with a specific interest in genetics and/or biotechnology

Different kind of members may be accepted at the discretion of the Board of Directors only.

In accordance with the Belgian law, a register of the ordinary members will be held at the registered office under the responsibility of the Board of Directors.

Article 7. Admission of the members

Every entity wishing to become a member shall apply in writing to the Board of Directors. The Board takes its discretionary decision at the simple majority of its members present or regularly represented. The Board shall decide if the person is accepted as an ordinary or an associate member. No appeal of the Board's decision is possible; the applicant shall be informed by ordinary letter.

Article 8. Fees

Each category of members shall pay an annual fee determined by the Board of Directors.

The members shall pay a maximum annual fee of 1.000 € The actual fee will initially be set at 50 €

Article 9. Resignation of members

Each member of the Association is free to resign at any time by sending a letter of resignation to the Board of Directors.

Article 10. Exclusion of members

A member may be excluded for violation of the statutes or for any action which may be harmful to the object of the Association. The exclusion of a member is pronounced by the General Assembly by a majority of two thirds of its members present or regularly represented.

Article 11. Consequences of the resignation or exclusion of a member

In case of exclusion or resignation, the member, or in case of death, his heirs, may not have any claim to the assets of the Association.

Chapitre III - Administration, direction, control

Article 12. Administration

The Association is directed by a Board of Directors, acting collegially, composed of a minimum of five and a maximum of nine directors elected and revoked by the General Assembly at the simple majority of the votes of present or regularly represented members.

The Directors are elected for a renewable term of two years by the General Assembly.

Not more than one half of the number of Directors on the Board may represent single issue Pan European organisations.

Article 13. Replacement of a Director

If a Director is nominated to replace another Director whose office has become vacant before the end of its term, the first ends the office of the Director being replaced.

Should it occur that the number of Board Directors is less than five, an extra-ordinary General Assembly should be held to replace the missing Directors.

Article 14. Remuneration of Director's Mandate

The Directors shall not receive any remuneration for their activities as such. If requested, they can be reimbursed for the expenses incurred on the benefit of the Association. They do not contract any personal obligation in the execution of their office.

Article 15. Composition of the Board of Directors

The Board of Directors shall choose a President, a Vice-President, a Secretary and a Treasurer within its members. They are chosen for a two-year, renewable, term.

The Board of Directors shall meet when called on by the President or, in case of absence, the Vice-President, or the eldest of the Board members each time the interest of the Association so requires. A meeting can be convened by mail, email, or fax. A meeting must be convened at least twice a year to have knowledge of the activities report of the Board and to approve the accounts.

Article 16. Proceedings of the Board

The meetings of the Board are presided by the President or in his absence by the Vice-President, or in their absence by the eldest of the present Board members.

Voting proxies are permitted and can be given to another member of the Board. However, each Board member may not hold more than one proxy.

The Board may only legitimately pass resolutions if at least one third of the Board members are present or represented.

The decisions are taken by a simple majority of votes. In case of a tied vote, the member presiding the meeting shall have a casting vote. The Board shall keep minutes of its meetings. The minutes are to be signed by the member presiding the meeting and filed in a special register.

Article 17. Powers of the Board

The Board of Directors has the widest powers to implement the objectives of the Association. It may exercise all the powers that are not specifically reserved to the General Assembly by the law or the statutes.

Article 18. Daily management

The Board may delegate the daily management of the association to the President and/or to one or more Board members.

May be considered as daily management: appointing employees and fixing their salaries; the financial administration; establishing the coming year's budget which must, however, be brought before the Board for approval; the execution of the Boards decisions; acting for the daily needs of the Association;

The daily managers can be revoked by decision of the Board by a simple majority of votes.

Article 19. Representation of the Association in public and judicial acts

The Board of Directors has general power to represent the Association. Legal proceedings, both as plaintiff and defendant, are to be followed by the Board of Directors.

Documents which bind the Association are validly signed in its name by the President and/or the daily manager and/or two Board members.

Article 20. Advisory Board

The Board of Directors may appoint advisors with certain skills in order to assist it in achieving the aim of the association.

The advisors are appointed by a simple majority of Board votes.

They serve for a limited mandate of one year renewable upon its term.

They may be invited to attend Board meetings but have no voting right.

Article 21. Auditor

Within the criteria of article 17§5 of the non-profit association law, an auditor is to be appointed each year by the General Assembly, and must not necessarily be chosen within the members of the Association.

The auditor's mission shall be to audit the accounts.

The office of the auditor is not remunerated except in the case of contrary decision by the General Assembly.

The auditor can be revoked by decision of an ordinary or extraordinary General Assembly by simple majority of the present or represented members.

Chapter IV - General Assembly

Article 22. Powers of the General Assembly

A resolution of the General Assembly is especially requested for the following :

- 1° amendments to the statutes;
- 2° election, appointment and dismissal of Board members;
- 3° election, appointment and dismissal of the auditor and the fixing of his remuneration in the exceptional case of his being remunerated;
- 4° giving discharge to the Board;
- 5° approval of the annual accounts, activity plan and budgets;
- 6° dissolution of the Association;
- 7° exclusion of members;
- 8° transformation of the Association in a « société à finalité sociale » (special form of company with a social aim).

Article 23. Composition of the General Assembly, Proxies

The General Assembly of the Association shall consist of the ordinary members of the Association.

The General Assembly elects a President within its members for a renewable two year term office. If the President is not present; the assembly shall assign a member to preside the meeting.

Each ordinary member is entitled to cast one vote.

The ordinary members may give a proxy to another member or to a third party.

Associate members may attend the General Assembly in an advisory but non-voting capacity. They are not taken into account in the quorums.

Article 24. Date, agenda and convening of the Ordinary General Assembly

The Ordinary general Assembly shall be held once a year at the time and place indicated in the notice.

The Ordinary General Assembly shall consider and approve the audited accounts, give discharge to the Board and to the auditors for the previous financial year and adopt a resolution on the budget for the coming year.

The General Assembly shall be convened by the Board upon fifteen days' notice. It can be convened by mail, email or fax, specifying the items on the agenda.

Article 25. Resolutions of the General Assembly, requested majorities

The resolutions of the General Assembly are to be adopted by a simple majority of votes, of its members present or represented, with the exception of the Association's by-laws and statutes which require special majorities.

In case of a tied vote the President of the Assembly, or in his absence the presiding member, shall have a casting vote.

Resolutions of the General Assembly are filed in a special register and signed by the President of the Assembly or by the presiding member in his absence.

Article 26. Amendment of the statutes

Any proposal for the amendment of the statutes of the Association will be combined with the calling of the General Assembly at least 30 days before the day of the meeting.

The notice shall contain the text of the proposed amendments.

The quorum to deliberate on an amendment to the statutes is reached if two thirds of the members are present or represented at the Assembly.

The decision shall obtain two thirds of the votes of the members either present or represented; however, an amendment to the purposes of the Association requires a majority of four fifths of the members either present or represented.

If two thirds of the members are not present or represented at the first meeting a second meeting may be convened no less than fifteen days thereafter. The proposal to amend the statutes may be considered at the second meeting even if less than two thirds of the members are present or represented.

Chapter V - Accounts and Budget

Article 27. Financial year, accounting obligations

The Association fulfills its accounting obligations in accordance with the relevant Belgian regulation.

The financial year shall begin on 1st January and shall end on 31st December of each year. The first financial year shall begin on the day of publication of the Articles of Association in the annexes of the Belgian State Gazette and ends on 31st December of the following civil year.

The Board of Directors shall submit the annual accounts (after audit) to the General Assembly for approval.

The approval of the accounts equals to giving discharge to the Board and to the auditor.

Chapter VI - Dissolution

Article 28. Means of dissolution, appropriation of the assets

The Association can be dissolved at any time if a resolution to this effect is adopted by the General Assembly. The resolution shall be adopted with the quorum and the majority required for a modification of the purposes of the association.

In case of dissolution the General Assembly shall appoint one or more person responsible for the liquidation of the assets of the Association.

The liquid assets after settlement of the liabilities shall be paid over to other non-profit making associations with similar objectives.

Chapter VII - Miscellaneous

Article 29. Jurisdiction

Unless otherwise specified in these statutes, the Belgian legal provisions and especially the law on non-profit making associations will apply.

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Brussels, 01/03/2005,

On behalf of Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP),
M. Cor OOSTERWIJK

On behalf of Genetic Interest Group (GIG),
M. Alastair Kent

On behalf of Heart EU, De Europese Cholesterol Patiënten Stichting,
M. Adrianus Cornelis van Bellen

