



# EURORDIS STATUTES

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Edinburgh, United Kingdom

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# Title I

## Objectives, Means of action and membership

### Article 1: Objectives

An association governed by the French law of July 1, 1901 and the decree of August 16, 1901, is founded between the members of the present statutes. Its title is EURORDIS - Rare Diseases Europe, also known as the European Organisation for Rare Diseases, which is a patient driven Federation of organisations active in the field of rare diseases.

EURORDIS is a unique non-profit alliance of rare disease patient organisations from many countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and services for patients.

To this purpose, the association undertakes activities in the following categories:

- advocating within European and International institutions for policies that address the needs of Rare Disease patients and their families
- promoting policies and services that bring solutions to people living with rare diseases
- advocating for policies that promote the development and equitable distribution of rare disease medicinal products and treatments
- contributing to rare disease research policy development
- encouraging rare disease patients and organisations to share information, experience and resources and providing them with the platforms to do so
- providing training programmes and resources for the purpose of empowering and strengthening the capacity of rare disease patient representatives
- facilitating patient advocates and patients active participation in policy implementation, research activities, product life cycle, healthcare and good practices
- gathering patient experiences and perspectives to inform policy making
- improving patients' and families quality of life by promoting their fundamental human rights, reducing inequalities, isolation and promoting their social inclusion
- providing services to patients, their families, patient advocates, patient organisations when they are of unique cross-diseases and cross-national high value
- raising public awareness

Its duration is unlimited.

EURORDIS was created in 1997 by four founding members: the Association Française contre les Myopathies, AIDES Fédération Nationale, Vaincre La Mucoviscidose, La Ligue Nationale Contre le Cancer. They are entitled to full membership of EURORDIS.

Thanks to their support, EURORDIS has been able to become established and maintain its operations as an independent organisation.

### Article 2: Headquarters

Its headquarters are located in Paris but may be transferred to another location by simple decision of the General Assembly.

Offices or branches of the organisation can be created in other countries, by decision of the Board of Directors.

## Article 3: Means of Action

The Association will use all means authorised by law, which may contribute to the achievement of its goals, notably:

- all means of diffusion and communication,
- provision of services,
- provision of fellowships for attendance of meetings or events
- signature of partnership agreements,
- creation of any legal entity or participation in any already existing legal entity,
- resorting to volunteers for specific action

## Article 4: Membership

The Association is a membership organisation composed of full and associate members. Further membership categories can be decided upon and added by the Board of Directors.

Only full members have voting rights.

Only European non-profit registered patient organisations can become or remain full members of EURORDIS and must comply with the membership criteria as decided by the Board of Directors. Patients Organisations who do not comply with all membership criteria can apply for associate membership.

To obtain full or associated membership, it is necessary to apply and to be approved by the Board of Directors.

Each full member designates one person to represent it at the General Assembly. Associate and other categories of members do not hold a vote. Only those full members who are up-to-date with their membership fee payments can vote.

The annual membership fees are set by the General Assembly.

Detailed membership criteria are maintained and updated by the Board of Directors and are included in the by-laws.

## Article 5: Membership resignation or loss

Membership in the Association may be ended by the following:

- a written letter of resignation addressed to the President of the Board,
- legal liquidation proceedings or dissolution, or relevant evidence that the organisation is no longer active
- dismissal by the Board of Directors in case of non-payment of dues,
- dismissal by the Board of Directors for gross breach of other Membership duties or any action likely to bring the Association into disrepute, after the member involved has previously been asked to provide an explanation.

## Title II

# Management and operations

### Article 6: Board of Directors

The Association is managed by a Board of Directors.

The number of directors is at least 6 and not more than 18.

The number of Directors for the coming year will be decided by the Board of Directors and reported to the Annual General Assembly.

The Directors are elected by the Annual General Assembly among individuals nominated by the full members of the Association, for a period of three years.

Individuals nominated to the Board of Directors must be nominated by a full member of EURORDIS. The nominated individual may be different from the representative to the General Assembly.

The Board of Directors may decide to dismiss a director in case of unjustified absence of the permanent representative from two consecutive Board of Directors Meetings.

Applications for the position of Director must be addressed to the President of the Board twenty one days before the General Assembly meeting by the legal representative of the member organisation.

In case of vacancy, resignation, or loss of the quality of member of the Association, the Board of Directors may replace a Director on a provisional basis until the next General Assembly. The mandate of the replacement director will expire at the same time at that of the original Director.

A third of the Board of Directors is to be renewed by election every year. If necessary, lots will be drawn to designate the renewed directors in the first years of the new Statutes.

The outgoing Directors are eligible for re-election at the end of their terms.

The Board of Directors selects Officers from its members, by secret ballot, composed of a President, a Vice-President, a Secretary, a Treasurer, an Officer and if necessary up to one additional officer.

All Officers are elected for a period of one year and are eligible for re-election at the end of their terms.

The roles and responsibilities of the Board of Directors and of the Officers are detailed in the by-laws.

### Article 7: Board of Directors Meetings

The Board of Directors meets at least once every six months, after convocation by the President, who establishes the agenda. It may also meet upon the request of one-quarter of the Directors.

Each Director may give his proxy to another Director. However, one Director may not hold more than one proxy.

The proceedings are valid only if at least one-third of the Directors are represented.

Votes are decided by simple majority. In the case of tied votes, the President casts the deciding vote.

A record of those attending is to be kept.

The minutes of the Board of Directors are recorded in a file of numbered pages, with no blank or erasures, signed by the President or Vice-President and the Secretary, and kept at the headquarters of the Association.

## **Article 8: Powers of the Board of Directors**

The Board of Directors retains extensive powers to make, in the name of the Association, all decisions which are not exclusively reserved to the General Assembly, and in particular:

- It decides on admission or expulsion of members of the Association.
- It oversees the activities of the Board of Officers which report to it.
- It decides on all questions relating to acquisitions, exchanges, disposal or rent, mortgages and loans for the pursuit of the Association's objectives.
- It sets the date for payment of dues by the members of the Association.
- It may delegate some of its responsibilities to one of the Directors for a specific task and for a limited period of time.
- It reports to the General Assembly.

This enumeration is not restrictive.

## **Article 9: Reimbursement of Directors' expenses**

The members of the Board of Directors are not entitled to receive any financial compensation for their duties as directors.

Only reimbursement of expenses incurred for the Association, with the corresponding documents, is possible.

Decisions on this subject are based on by-laws approved by the Board and available to all members.

## **Article 10: Role of the Board of Officers**

The Officers of the Association, as described in the article 5, assist the President in the implementation of decisions of the Board of Directors. Officers consult, if necessary by telephone conference, at least four times a year.

The President represents the association in all civil proceedings.

The President orders the distribution of funds. The President may delegate his/her powers to the Vice-President by written mandate.

The President acts for the Association in court, either as plaintiff or defendant.

In case of legal proceedings, the President may only be replaced by a proxy who acts by means of a special authorisation.

Missions of Officers and Directors are specified in the by-laws.

The representative of the Association must be in possession of all their civil rights.

## **Article 11: Operational Entities**

In order to help the Board of Directors to fulfil its missions, EURORDIS' management will rely on several operational entities.

### **Article 11-1: Council of the National Alliances (CNA)**

Members of the Council of the National Alliances are all European organisations that are recognised as "National Alliances of Rare Disease Patient Organisations" by the Board of Directors.

The major tasks of the Council are to strengthen the European Network of National Alliances, to participate in relevant EURORDIS activities and to provide advice and expertise to the Board of Directors.

The criteria of that recognition and the Council's role, organisation and procedure will be established in the Council by-laws.

### **Article 11-2: Councils, Working Groups, Task Forces, Steering Committees, Editorial Boards and other entities**

Councils, Working Groups, Task forces, Steering Committees, Editorial Boards and other committees may be created as needed for the purpose of assisting and providing advice in the context of specific activities or projects of the association. The size and life-span of these entities will vary according to the tasks entrusted to them and their creation is validated by the Board of Directors. The participants of these entities will be involved in the name of EURORDIS and must report to EURORDIS.

The composition, governance, organisation and mandate of each entity will be established in separate by-laws.

## **Article 12: Rules of the General Assembly**

The General Assembly of the Association consists of all the members mentioned in article 3 and whose voting rights are defined in the same article.

It is possible to vote by proxy under the following conditions:

- the proxy must be established by a written document,
- the person who detains the proxy must also be a full member of the Association.
- Both parties must be up-to-date with their membership fees.

Each member present may hold no more than five proxies.

It is possible to vote remotely provided that an adequate system, approved by the Board of Directors, is set in place, and that adequate resources for the arrangement of this system exist.

The General Assembly will meet once a year, and each time that it is called by the Board of Directors, or upon request of at least one-fourth of the members of the Association. The General Assembly convocation must include the agenda, which is set by the Board of Directors.

The Officers of the Assembly are those of the Board of Directors. In all cases, the General Assembly must be notified individually to all members at least fifteen days before the meeting.

Its proceedings are valid no matter how many members are present, except for the provision in article 16.

Voting, by secret ballot, is by simple majority of votes cast.

The Association's management and financial reports are presented at the General Assembly.

It approves the accounts of the previous financial year, votes the budget for the following financial year, discusses the items which have been placed on the agenda and proceeds, if necessary, to the election of members of the Board of Directors.

Minutes of the General Assembly are recorded.

The minutes are recorded in a file of numbered pages with no blank spaces or erasures signed by the President and the Secretary, and kept at the headquarters of the Association.

The annual report and the accounts are available on the EURORDIS website to all members and are mailed on request.

## Title III Financial Means

### Article 13: Financial Means

The income of the Association consists, amongst others, of:

- 1. membership fees
- 2. grants from the European Union, its Members States and regions, departments, municipalities, and any public or private establishments,
- 3. revenues from its assets,
- 4. revenues of donations the use of which is authorised during the current financial year,
- 5. resources created in exceptional cases and if required, with the approval of the competent authority,
- 6. proceeds of sales and remuneration for services rendered.
- 7. all other resources authorised by French law.

### Article 14: Accounts

Accounts are kept, with a balance sheet, a profit and loss statement and annexes produced on a yearly basis. The use of the funds from all the grants awarded during the last financial year must be accounted for each year to the Préfecture of the département and the relevant Ministries.



## Title IV

### Amendment of the Statutes Dissolution

#### Article 15: Modification of Statutes

The Statutes may be modified by the General Assembly acting at an extraordinary meeting, upon proposal by the Board of Directors, or upon proposal of at least one quarter of the full members of the Association.

In both cases, the proposal of amendment is mentioned in the agenda of the next General Assembly, which must be notified to all members of the Assembly at least fifteen days in advance.

At least a quarter of the full members must be present or represented at the Assembly.

If this proportion is not reached, the assembly is convened again, after at least a fifteen-day interval and this time it may carry out its deliberations validly whatever the number of members present or represented.

In all cases, the statutes may only be modified with a majority of two-thirds of the votes cast.

#### Article 16: Dissolution

The Extraordinary General Assembly decides on the dissolution of the Association. It is convened especially for this purpose under the conditions set out in the previous article.

At least half plus one of the full members must be present.

If the proportion is not reached, the Assembly is convened again, after at least a fifteen-day interval, and this time it may carry out its deliberations validly with whatever the number of members and proxies.

In all cases, the dissolution may not be voted except with a majority of two-thirds of the votes cast.

#### Article 17: Liquidation

In case of dissolution, the General Assembly designates one or more commissioners to be in charge of the liquidation of the Association. The net assets will be allocated to one or more analogous establishments, either a public institution or a registered charity, or to institutions falling under article 6, paragraph 2 of the French Law of July 1st, 1901, modified.

#### Article 18: Public information

Decisions of the Extraordinary General Assembly under articles 14, 15, 16 are addressed without delay to the Préfecture of the département.

## Title V

### Monitoring and By-laws

#### **Article 19: Monitoring**

The President must inform the Prefecture of the Department or the Sous-préfecture of the district in which the Association has its headquarters, of all changes in the administration or the direction of the Association. The annual report and the accounts are addressed yearly to the Préfecture of the département.

#### **Article 20: By-laws**

The Board of Directors is responsible for drafting, adopting, monitoring and updating the by-laws which will determine the application details of these Statutes.

These By-laws will be available to the General Assembly, as will any modifications.