RARE
DISEASES
INTERNATIONAL

Rare Diseases International (RDI) Statutes

Statutes adopted in English at the RDI Annual Membership Meeting,

10 May 2018, Vienna , Austria.

A French translation of these Statutes will be submitted to the French Prefecture de Police

for the legal incorporation of RDI

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Title I
Objectives, Means of action and membership

Article 1: Objectives

The Association, whose name is Rare Diseases International (RDI), is a patient driven Federation of organisations active in the field of rare diseases and operating under French jurisdiction.

Rare Diseases International (RDI) is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI brings together national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations to create the global alliance of rare disease patients and families.

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

- advocating within 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
  advocating for, promoting or facilitating the provision of 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.

RDI was officially launched on May 28, 2015 at the RDI Inaugural Meeting in Madrid, Spain. RDI was initiated by EURORDIS in partnership with the National Organization for Rare Disorders (US), the Canadian Organization for Rare Disorders, the Japanese Patient Association, the Russian Patient Union and Rare Voices Australia.

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 Council of Directors.

Article 2: 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,
- advocating for, promoting or facilitating the 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 actions,

Article 3: Membership

The Association is a membership organisation composed of full and associate members.
Only full members are eligible to be candidate and elected to the Council of RDI.
Only full members have voting rights.

Associate members are entitled to participate in all activities, but cannot stand for election to the Council nor do they have voting rights.

Only non-profit, registered, rare disease patient organisations can become or remain full members of RDI and must comply with the membership criteria as decided by the Council of RDI. Patient Organisations who do not comply with all membership criteria can apply for associate membership. One, or all, of these criteria could be waived by the Council of RDI.

To obtain full or associated membership, it is necessary to apply and to be approved by the Council of RDI. The Council of RDI makes the final decision regarding membership applications, and is not obliged to disclose the reasons of this internal decision.

Each full member designates one person to represent it at the annual General Assembly.

The Agenda of the General Assembly is prepared by the Council.

The annual membership fees are approved by the General Assembly.

Detailed membership criteria are maintained and updated by the Council of RDI and are included in the by-laws.

Article 4: Membership resignation or loss

Membership in the Association may be ended by the following:

- a written letter of resignation addressed to the Chair of the Council,
- legal liquidation proceedings or dissolution, or relevant evidence that the organisation is no longer active
- dismissal by the Council of RDI in case of non-payment of dues,
- dismissal by the Council of RDI 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 5: Governing Council

The Association is managed by a Governing Council of Directors (known as the Council).

Members of the Governing Council shall consist of not less than five (5) and no more than nine (9) Directors. The actual number of Members to be voted in for any given election term will be set by a majority vote of the Council prior to the election During a term, the number of members of Council may be changed by vote of a majority of the entire Council to reflect the resignation or removal of a Council member.

The Members are elected by Full Members of the Association from individuals nominated by the full members of the Association, for a period of three years. Only Full Members of RDI have the right to participate in the election of Council Directors.

Each Full Member of RDI may submit a nomination of an individual representative of their Organisation to serve on the Council.

- Full Members may only submit one (1) nomination of an individual representative per election.
- No RDI member Organisation can have more than one representative on the Council at any given time.
- Outgoing Directors on the Council are eligible to be nominated by their Organisation for re-election.

Directors are elected as individuals, not as representatives of their nominating member organisation, and are required to put the best interests of RDI ahead of any other consideration.

The Council of Directors selects Officers from its members, composed of a Chair, Secretary and Treasurer.

- The Council may elect additional Officers such as Vice Chair.
- No person may hold more than one office in the Organisation concurrently.

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

Article 6: Council Meetings

The Council will meet 4 to 12 times a year (normally via teleconference or web conference), with at least one (1) physical meeting each year.

- Given the global nature of the Organisation, every attempt should be made to accommodate reasonable meeting dates, locations and times to ensure members have equal opportunity to participate.

The Chair decides on the date and time of the meeting and set a provisional agenda with consultation from the other directors, which is reviewed and approved at the beginning of the Council's Meeting. Two (2) or more directors can also initiate a Council Meeting, which the chair cannot reject.

Council members will be made aware of all meetings by the Secretary at least thirty (30) days in advance through written communication – physical or electronic. In general, all documents will be sent to the Council Directors by the Secretary seven days (7) in advance.

If the Directors consent, in writing, to any action to be taken by the Council, such action shall have the same force and effect as if taken at a duly called meeting.

A quorum shall consist of at least half of the Council plus one and shall not include a proxy of an absent Director, unless otherwise approved by all members of the Council Meetings of the Council.
When votes are necessary, the rule is a simple majority. In case of split vote, the Chair has the pre-eminence.

A record of those attending is to be kept in the minutes of the Council meetings.

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

Article 7: Powers of the Council

The Council 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. The rationale and process for expulsion should be defined and adherence to these procedures should be made transparent in any instances resulting in expulsion.
- It oversees the activities of the Council 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 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 8: Reimbursement of Directors' expenses

The members of the Council 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 Council and available to all members.

Article 9: Role of the Council of Officers

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

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

The Chair represents the association in all civil proceedings.

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

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

Article 10: Operational Entities: Committees & Working Groups

In order to help the Council fulfil its missions, RDI's management will rely on several operational entities, such as committees and working groups.

The Council may establish Committees & Working Groups with such powers and duties as may be deemed necessary or advisable by the Council to investigate or fulfil policies and activities that further the objectives of the Association.

Each Committee or Working Group is established with a clear purpose and specific objectives / deliverables and a timeframe. These terms are approved by the Council. The Committees and Working Groups are accountable to the Council and shall report back to the Council about their activities and decisions.

The size and life-span of these entities will vary according to the tasks entrusted to them. The participants of these entities will be involved in the name of RDI and must report to RDI.

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

Article 11: 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 remotely provided that an adequate system, approved by the Council, is set in place, and that adequate resources for the arrangement of this system exist.

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

The General Assembly must be notified to all members at least thirty (30) days before the meeting. Such written notice shall be provided by surface mail or electronic means.

The Association's activity and financial reports are presented at the General Assembly. The General Assembly approves the accounts of the previous financial year, votes on the budget for the following financial year, discusses the items which have been placed on the agenda.

The Business agenda of the General Assembly can be presented face to face or by electronic means or a blend of both, aiming to consult as many members as possible, provided that this is possible.

There is no quorum for the Annual General Assembly. RDI will seek to engage as many members as possible and will keep a record of members who have participated. The members' opinions recorded are the opinions or votes expressed in the meeting or by electronic means; results are anonymised.

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

The annual Financial Reports are available on the RDI website to all members and are mailed on request.

Title III
Financial Means

Article 12: Financial Means

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

- 1. membership fees
- 2. grants from 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 conference fees, training fees, sales and remuneration for other services rendered.
- 7. all other resources authorised by French law.

Article 13: 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 14: Modification of Statutes

The Statutes may be modified by the General Assembly acting at an extraordinary meeting, upon proposal by the Council, 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 thirty (30) days in advance.

At least half plus one of the full members must vote (physically or electronically).

If this proportion in 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 15: 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 vote (physically or electronically).

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 16: 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 17: 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 18: Monitoring

The Chair 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 19: By-laws

The RDI By-laws are the set of rules under which the Association operates. The Council 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 presented to the General Assembly and available on RDI website, as will any modifications.