



RARE DISEASES INTERNATIONAL

By-Laws

These By-Laws regulate the operation of the Rare Disease International (RDI), in conjunction with the Statutes adopted at the RDI Annual General Meeting on 10 May 2018, Vienna, Austria.

These By-laws are adopted by the Council of RDI on April 9, 2020 and presented at RDI Annual General Meeting on 18 May, 2020.

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ARTICLE 1- REGISTRATION

Rare Disease International (hereinafter refer as “RDI”, is a legal entity registered in the Republic of France on December 7, 2018.

ARTICLE 2 - INTERPRETATION

In these Articles, save as the context otherwise requires: -

“patient” means any person who is suffering from any rare disease, illness, syndrome, organ impairment or disability, or such disease to be recognized by the Council;

“Patient Representative” means a person that is significant for a patient or their care, who can represent that patient, for example a partner, parent, family member or relative;

"Full Member" means any organization admitted as a Full Member of RDI, whose name appears on the Register of Members. A Full Member has voting right at all General Meetings;

“Associate Member” means any organization admitted as an Associate Member of RDI, whose name appears on the Register of Members. An Associate Member does not have voting right at all General Meetings;

“Strategic Partner” means any global inter-governmental, professional, academic, industrial or civil society organization designated by RDI who shall be able to ensure and enhance the well-being of patients with rare disease worldwide.

"Council" means the governing body of RDI;

"Council Member" means representative who is nominated by Full Member duly elected in the election of Council;

"Chairperson" means the person for time being elected to hold the office of the chairperson of RDI;

"Vice-Chairperson" means the person for time being elected to hold the office of the Vice-Chairperson of RDI;

"Secretary" means the person for time being elected to hold the office of the secretary of RDI;

"Treasurer" means the person for time being elected to hold the office of the treasurer of RDI;

"Secretariat" means the office set up by RDI taking up operations and any other duties assigned by the Council;

"Member" means any Full Member and Associate Member of RDI, and "Membership" shall be construed accordingly;

"By-Laws" means these By-laws;

"Articles" means the original or restated articles, deleted, new or amended by these By-Laws,;

"Ordinary resolution" means a resolution passed by a majority of not less than 50% casting on that resolution;

"Special resolution" means a resolution passed by a majority of not less than two-thirds (2/3) of the votes cast on that resolution.

In the interpretation of these by-laws, words in the singular include the plural and vice-versa, words in one gender include all genders, and "person" includes an individual, patient organization, partnership, and unincorporated organization.

ARTICLE 3 - MEMBERSHIP

3.1. Membership Categories

RDI shall consist of two categories of member organizations: Full Member and Associate Member.

3.2. Full Member

To become Full Members, organizations shall meet all of the following five criteria. The Council has discretion to determine whether each criterion has been met or to waive the criterion.

- (a) Be a non-profit and non-governmental organization
- (b) Have a legal status appropriate to its country of origin, with a written constitution and/or by-laws. If no appropriate legal status exists in the country of origin, the Council shall determine how this criterion is fulfilled.
- (c) Be an international or regional organization, or an umbrella group representing one or more rare disease or be a national organization that represents multiple rare diseases.
- (d) Demonstrate commitment to patients with rare disease in their guiding statements, such as their vision, mission or organizational objectives, and their activities.
- (e) The organization must be patient-driven. This means that the needs and views of patients drive the organization's strategy, policies and activities in a significant way and that the organization is capable of representing the needs and views of these patients. Organizations must demonstrate that they use at least one of the following methods:
 - (1) Demonstrate that the majority of the organization's voting members are patients, patient representatives or patients' organizations with the power to nominate and elect their own governing body.
 - (2) Demonstrate that the majority of the organization's governing body are patients, patient representatives, or representatives of patients' organizations.
 - (3) Demonstrate that the organization has a governance structure which ensures that it is patient-driven i.e. the needs and views of patients drive the organization's strategy, policies and activities in a significant way and that the organization is capable of representing the needs and views of these patients. A description and/or illustration of the governance structure shall be included in the organization's application.

An organization may request waiver or unique or alternate fulfillment of one or more criteria for full membership. The Council shall consider the request along with any submitted rationale or

justification. The Council has sole discretion to grant any waive or exception, including delayed fulfillment of one or more criteria. The Council shall document in the minutes the deliberations and resolution, along with rationale for its decision.

3.3. Associate Members

RDI Associate Members may be rare disease specific or related organizations that are not eligible to become RDI Full Members but meet the following four criteria:

- (a) Be a non-profit and non-governmental organization
- (b) Have a legal status appropriate to its country of origin, with a written constitution and/or by-laws. If no appropriate legal status exists in the country of origin, the Council shall determine how this criterion is fulfilled.
- (c) Be an international or regional organization, or an umbrella group representing one or more rare disease or be a national organization that represents multiple rare diseases
- (d) Demonstrate commitment to improving various aspects of rare disease in their guiding statements, such as their vision, mission or organizational objectives and their activities. The organization may be a multi-stakeholder umbrella coalition or alliance.

3.4. Membership Application

In order to become a RDI member, the applying organization must complete a membership application form available from RDI. They must present on and with this form any information requested. The Council may give authorization to the Secretariat to assess the applying organization's suitability for membership and the appropriate type of membership. Approval or rejection of a membership application is determined by the Council according to 3.2. and 3.3. of this Article of these By-Laws.

3.5. Membership Fees

Membership fees may be set and amended by the Council.

3.6. Termination of Membership

An organization's membership may be terminated by the following:

- (a) A written letter of resignation addressed to the Chairperson of the Council.
- (b) Legal liquidation proceedings or dissolution.

The Council, after due deliberation, may recommend the suspension or termination of any organization's membership of RDI. Sufficient cause for suspension or termination shall be:

- (a) Violation of any by-law, rule, policy or practice duly adopted by the Annual General Meeting and/or the Council of RDI.
- (b) Any other conduct materially prejudicial to the interests of RDI.
- (c) Non-payment of fees for membership of RDI.
- (d) A deviation from the elements in the application from which membership was granted
- (e) A significant reputation controversy or actual actions which may affect the reputation of RDI.

Such suspension or termination shall be ratified by a vote of the Council. Suspension can be immediate. Termination, specifying the grounds for such action shall have been given to the member organization in question at least twenty days' notice before final action is taken. At the meeting at which such action is proposed to be taken, the Member or Associate in question shall be given the right to appear to present any defense or mitigation to such charges before the aforementioned vote of the Council is taken.

ARTICLE 4 – STRATEGIC PARTNER

To ensure and enhance the well-being of patients living with rare disease world-wide, RDI may, from time to time, designate and collaborate with any global or regional inter-governmental, professional, academic, industrial or civil society organization as its Strategic Partner.

Such strategic partnerships are decided by the Council, on the ground of arguments and objectives of the collaboration.

ARTICLE 5 - GENERAL MEETING

5.1. General Assembly

The General Assembly of RDI shall consist of one delegate from each full member organization, and should strive to reflect an international presence. This delegate shall be known as an organization's RDI Representative.

General Assembly can be in presence or virtual online.

5.2. Annual Meetings

An Annual Meeting of the General Assembly shall be held once in every calendar year and not more than 18 months shall pass between one Annual Meeting and the next, unless this period is extended by the Council, and at such a place and hour as the Council may determine.

Matters subject to the approval by voting of the Annual General Meeting shall include:

- (a) Annual Activity Report for the previous year.
- (b) Annual accounts for the previous financial year.
- (c) Annual Action Plan and budget for the current financial year.
- (d) Any other such business as may properly come before the meeting.

5.3. Extraordinary Meetings of the General Assembly

Extraordinary Meetings of the General Assembly may be called by the Chairperson of the Council who shall fix the time and place for the meeting. The Chairperson may call an Extraordinary Meeting at the request in writing of not less than twenty percent of the Full Members. Written notice of the date, time and place of each extraordinary meeting shall be given to each Member within 7 to 14 days.

5.4. Voting at Meetings

Each Full Member of RDI shall have the right to cast one vote at Annual and Extraordinary Meetings of the General Assembly. Such vote may be cast in person by the Member's RDI Representative, or by written proxy duly executed by or on behalf of such Member. Proxy Holder must be a Full Member of RDI. No Proxy Holder may hold more than five proxy votes to be cast at the Meeting.

5.5. Casting Vote

In the case of an equality of votes, the chairperson of the Meeting shall be entitled to a second or casting vote.

5.6. Quorum of General Meetings

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.

ARTICLE 6 - THE COUNCIL

6.1. Role of Council

The Council elected by the General Assembly shall be the executive body of RDI, responsible to the General Assembly of its members.

The Council shall be responsible for all affairs between meetings of its members, and shall in particular be responsible for the execution of the decision taken by the General Assembly.

The Council prepares the General Assembly, including the validation of the activity report and financial report of the previous year, the action plan and budget of the current year, the resolution and other relevant documents submitted to the votes of the General Assembly.

The business and operations of RDI shall be governed, strategized and directed by the Council.

The Council shall supervise and instruct on the work of the Secretariat.

The Council may delegate to committees and working groups as it may see fit.

6.2. Quorum of Council

The Council shall consist of not less than FIVE (5) and no more than NINE (9) members.

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.

6.3. Election of Council

Each Full Member may nominate one (1) representative to stand for election of Council. Election shall be conducted every year online the month prior to the General Assembly Meeting. Only Full Members shall have ballot to vote in the election. No Member Organization can have more than one elected member on the Council at any given time.

6.4. Term of Council Membership

Council Member shall be elected for a three-year term. Outgoing Council Members are eligible to stand for re- election. A Full Member cannot nominate another representative to replace its elected representative's Council Membership prior to the end of his / her term.

6.5. Termination of Council Membership

Membership of Council shall be terminated by:

- (a) the Council Member is no longer a representative of RDI Member who nominates him / her.
- (b) the Full Membership of the Member organization who nominates him / her is discontinued.
- (c) Death.
- (d) Dismissal by the Council. A Council Member shall be dismissed by a two-thirds vote of the other Council Members.

6.6. Vacancies

In the case of a vacancy prior to the end of the term, the position will be filled by a candidate from the previous election with the next highest number of votes. In the case of a tie between two candidates, the Chairperson reserves the right to choose between them.

6.7. 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.

The Chair decides on the date and time of the meeting and sets 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.

Special meetings of the Council may be called by its Chairperson who shall fix the time and place for the meeting. The Chairperson shall call a Special Meeting of the Council at the request in writing of not less than three (3) of its members. At the beginning of the Council Meetings, the Chair ask if all members of the Council agree to hold the meeting and if there are any changes proposed to the agenda

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 who attend the Meetings.

6.8. Voting

A quorum shall consist of at least half of the Council plus one.
When votes are necessary, the rule is a simple majority. In case of split vote, the Chair has the pre-eminence.

6.9. Remuneration

The Council Members shall not receive any salary or other remuneration for their work as such; expenses incurred for the benefit of RDI shall be reimbursed if requested.

ARTICLE 7 – OFFICE BEARER

7.1. Officers

RDI office bearers shall consist of Chairperson, Secretary and Treasurer. The Council may elect additional Officers such as Vice Chair.

No Council Member may hold more than one office concurrently.

7.2. Election and Term of Office Bearers

The office bearers shall be elected by and from the Council for a term of one year. Office bearers may be re-elected to the same position.

7.3. Vacancy

Any office bearer may resign or be dismissed by the Council from whose post. A vacancy in any office occurring for any reason, including the dismissal, shall be filled by another Council Member for the remainder of the term.

7.4. Chairperson

The Chairperson shall preside at all General Assemblies of RDI, the Council; and shall be an ex-officio member (with the right to vote) of all committees.

7.5. Vice Chairperson

The Council may appoint a Vice Chairperson. The Vice Chairperson shall chair General Assembly of RDI, the Council and all Committees in the absence or disability of the Chairperson. He/she shall also perform such other duties as may be assigned from time to time by the Chairperson or Council.

7.6. Secretary

The Secretary shall keep or cause to be kept an accurate record of the proceedings of the General Assembly and shall give or cause to be given notice of all General Assemblies and of the Council. He/she shall also perform such other duties as may be assigned from time to time by the Chairperson or Council.

7.7. Treasurer

The Treasurer shall supervise the annual budget and its regular follow up, the annual financial accounts and statements, the audit reports as well as for their presentation to the Council and General Assembly. He/she shall supervise the administration and good use of funds, including policies on investment, reimbursement of funds, and signatures on accounts, to be adopted by the Council.

As per the Memorandum of Understanding between RDI and EURORDIS (2019-2023) the Treasurer shall oversee and work with the EURORDIS Financial Unit who handle the day-to-day financial business of RDI, including disbursements, accounting and auditing procedures. He / she shall also perform such other duties as may be assigned from time to time by the Chairperson or Council.

ARTICLE 8 – COMMITTEES AND WORKING GROUPS

The Council may constitute and delegate specific authorities and duties to committees and working groups, which from time to time may be required, to pursue the policies, programs, projects, commitments and membership guidelines it has established.

ARTICLE 9 – SECRETARIAT

The Secretariat is responsible for leading RDI in achieving its vision and mission. The Secretariat will oversee the day-to-day functions of the organization as well as hold responsibility for carrying out its plans and programs as determined by the Council and approved by General Assembly in the annual strategic action plans. They will report directly to the Council of RDI.

The Secretariat will be comprised of a Director who will oversee staff employed by the organization and those on contract, and will represent RDI and manage its affairs, in regular liaison with the Officers of the Council.

The Director is responsible for supporting the Chair and the Council in their tasks and in governing RDI as defined in these by-laws. This responsibility includes assisting in the formation of strategy, action plans, budgets, membership applications, and operating procedures; for managing staff and volunteers, securing resources; deploying advocacy; communication and other operational activities as required.

ARTICLE 10 - AMENDMENT OF STATUTES AND BY-LAWS

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 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.

The 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.

ARTICLE 11 - FINAL PROVISIONS

All the powers not assigned by law or the Statutes or the By-Laws to other bodies are vested in the Council.

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