



**BYLAWS OF
RARE DISEASES INTERNATIONAL (RDI)**

FINAL VERSION

PREAMBLE

RARE DISEASES INTERNATIONAL

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.

WHY CREATE RARE DISEASES INTERNATIONAL?

Around the world, rare disease patients are faced with common challenges derived from the rarity of their conditions and aggravated by the low priority given to rare diseases globally and locally. Many rare diseases are chronic, progressive, degenerative, and life-threatening. They are disabling: the quality of life of patients is often compromised by the lack or loss of autonomy and support. A majority of rare diseases are genetic and many affect children.

The inability to obtain an accurate diagnosis and lack of treatments and care are challenges faced by rare disease patients everywhere, and these difficulties prove greater in developing nations. Addressing rare diseases on an international level is critical to reducing health inequalities between patient populations worldwide to ensure people living with a rare disease have access to the same resources as patients with more common conditions.

Today, most international rare disease initiatives are ad hoc and linked to a particular disease. People living with a rare disease need to join together in a structured approach to create a global rare disease community to exchange of experiences and speak with a common advocacy voice.

THE VISION

- RDI recognises that people living with a rare disease are facing similar challenges irrespective of where they live in the world. People living with one of the more than 6 000 rare diseases known within one of the 200 countries, share a common interest to address their comparable or specific needs.

- Through its work, the hope is that RDI will ensure that people living with a rare disease worldwide and their families will experience better recognition and support improved health or social services, and overall, better life.
- RDI is purpose-driven, principles-led and patient-driven

AN INITIATIVE OF EURORDIS JOINTLY WITH ITS PARTNERS AROUND THE WORLD

The idea to connect existing rare disease patient organisations addressing specific rare diseases or working as a national umbrella was present in the mind of many patient advocate leaders around the world but no one had the capacity to do it.

In 2009 **EURORDIS** included as a high priority in its **five-year strategy 2010-2015** that rare diseases become an international movement and gain visibility and influence in international instances.

Since 2009, EURORDIS has signed agreements, with national rare disease alliances around the world that included common objective to create an international movement of rare disease patients. With the **National Organisation for Rare Disorders (NORD, USA)** in 2009, the **Canadian Organisation for Rare Disorders (CORD, Canada)** in 2012, the **Japanese Patient Association (JPA, Japan)** in 2013, the **Russian Patients Union (RPU, Russia)** and **Rare Voices Australia (RVA, Australia)** in 2015.

In March 2012, the EURORDIS Board of Directors adopted the **EURORDIS CEO's proposal** to create a Rare Diseases International network to expand the movement of rare diseases internationally, provide mutual support between patient organisations and be able to speak with one voice.

RDI was officially launched on **May 28, 2015** at an **RDI Inaugural Meeting in Madrid, Spain** held alongside the EURORDIS Membership Meeting.

Full history can be found on the website.

Underlying Premises of RDI By-Laws

RDI is an international network initiated by and currently embedded in EURORDIS.

As such RDI is an operational entity of EURORDIS, operating within the legal statutes and internal by-laws of EURORDIS.

RDI is a membership-based not –for-profit international non-governmental organisation.

RDI members and RDI Council are empowered with full authority to undertake their roles and responsibilities, as decision makers within these RDI By-Laws.

No member organisation or individual duly appointed or elected to act on behalf of RDI, assumes any legal or financial liability; these remain with EURORDIS.

RDI retains political independence from EURORDIS, including its strategy and objectives, its membership, its advocacy, and its actions. As such the RDI Council functions independently and is solely accountable for its decisions. Therefore, in principle, EURORDIS and RDI could have divergent opinions or positions. This is accepted by the EURORDIS Board of Directors and Executive Staff as well as by the RDI Council.

The purposes of these RDI By-Laws are:

- (a) To establish the responsibilities and authorities delegated by the EURORDIS Board of Directors to the operational entity RDI and its RDI Council,
- (b) To position and empower RDI with political autonomy and a moral personality to carry on its mission and strategy,
- (c) EURORDIS being the legal personality hosting RDI, to define the support services and control provided by EURORDIS' Board of Directors and its staff over legal and financial responsibilities so to protect the liabilities of EURORDIS, ensure quality administrative services, while the RDI Council be empowered to manage its operations.

The intention is to incorporate RDI as a distinct legal entity within the next 3 years. This may be necessary for instance for its representation in international bodies or its growth. To do so, RDI will need to have catalysed the financial resources and technical capacities; therefore 3 years may be necessary, but these milestones may be reached earlier or later. Hence, the hosting of RDI by EURORDIS should be seen as transitional but in an enough robust manner to last.

ARTICLE 1 – NAME

The name of the Non-Profit International Non-Governmental Organisation shall be known as **Rare Diseases International**, and shall herein be referred to as the “Organisation” or “RDI.”

ARTICLE 2 - DEFINITIONS/INTERPRETATION

2.1 Definitions:

In this RDI By-Laws, unless the context otherwise requires:

- "**EURORDIS statutes**" refers to the legal Statutes incorporating EURORDIS;
- “**EURORDIS By-Laws**” refers to the internal By-Laws of EURORDIS;
- "**Organisation**" means Rare Diseases International (RDI);
- "**By-Laws**" means this by-laws;
- "**Articles**" means the original or restated articles, deleted, new or amended from these By-Laws,;
- "**Council**" means the Governing Council of the Organisation;
- "**Director**" means a member of the Council;
- "**Member**" means the members of the Organisation as defined in article 4;
- “**Partners**” Entities with whom RDI has working relations and/or with which RDI cooperates to promote the cause of rare diseases;
- "**Meeting of members**" or “**Membership Meeting**” means the annual meeting of RDI members or a special meeting of RDI members as defined in article 5;
- "**Officer**" means those officers identified in articles 8 and 9;
- "**Ordinary resolution**" means a resolution passed by a majority of not less than 50% plus 1 of the votes cast 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.

2.2 Interpretation - In the interpretation of this 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 organisation, partnership, and unincorporated organisation.

2.3 Procedural Policy -The Council may establish a policy outlining any procedural rules applicable to meetings of the members, the board or committees.

ARTICLE 3 - PURPOSE

3.1 Mission

Rare Disease International (RDI) aims to be a strong common voice on behalf of people living with a rare disease around the world.

3.2 Objectives

- To promote rare diseases as an international public health and research priority through public awareness and policy-making
- To represent its members and people living with a rare disease at large, in international institutions and forums
- To enhance the capacities of its members through information, exchange, networking, mutual support and potentially joint actions

3.3 Principles

- RDI promotes patient empowerment, patient community building, patient preferences, patient active participation/engagement
- RDI works collaboratively with its members and in partnership with its stakeholders
- RDI aims at solidarity, equity and social justice
- RDI behaves with respect, benevolence and trust
- RDI acts with authenticity, integrity and independence

ARTICLE 4 - MEMBERS

4.1 Classes of Members

There shall be 2 classes of members of the Organisation: Full Members and Associate Members. Only full members are eligible to be candidate and elected to the Council. Only full members can vote at the annual Membership Meeting on the Annual Report, Annual Work Programme, Council candidates, most resolutions according to these By Laws. Associate members are entitled to participate in all activities.

4.2 RDI Full Members

4.2.a Main Criteria for Full Membership

Organisations must fulfil one of the following criteria in order to be considered for Full Membership in RDI:

- National Alliances for Rare Diseases - federate patient organisations from a wide range of diseases within their particular country.
- International Federations for Rare Diseases worldwide - union of patient groups from several countries and continents representing the same disease or the same family of diseases.
- Pan-regional networks for Rare Diseases worldwide – coalition of national Rare Disease Alliances and other patient organisations from a given region, such as Asia-Pacific or Scandinavia.

4.2.b Additional Criteria for Full Membership:

- Must be a rare disease organisation, according to the definition of rare disease adopted by their own country, the European Union, the WHO, or any other legitimate jurisdiction.
- Must be non-profit and non-governmental.
- May be an international, regional, national or umbrella group.
- Must have a legal status corresponding to one of these situations:
 1. A fully incorporated organisation with 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 this criterion may be waived at the discretion of the Governing Council;
 2. An international umbrella organisation which acts on behalf of members from several countries but which does not have independent legal incorporated status may have its application submitted by one of its member organisations with legal status. The applicant must be able to demonstrate that the umbrella organization does act as a collective on behalf of its members, for example, by adopting common positions on key issues, providing integrative services (e.g., screening, registries, research) or taking joint action (e.g., education, advocacy, recruitment). Only the name of the international organisation will be listed as an RDI Member
 3. A patient group with an international scope for an “extremely” rare disease; the organisation should be unique with respect to this patient population.
- Must be a patient-driven organisation. Around the world, organisations achieve this in different ways. Organisations must demonstrate that they use at least one of the following methods:

1. The majority of the Organisation's voting members are patients, patient representatives or patients' Organisations with the power to nominate and elect their own governing body.
 2. The majority of the Organisation's governing body are patients, patient representatives, or representatives of patients' Organisations.
 3. The Organisation can demonstrate that it has a governance structure which ensures that it is patient-driven i.e. the needs and views of patients drive the Organisation's strategy, policies and activities in a significant way and that the Organisation is capable of representing the needs and views of these patients. This governance structure must be described and illustrated in a written letter which should accompany the Organisation's application.
 4. RDI recognises that local situations vary considerably – legally, politically, culturally, economically, and otherwise – hence there must be flexibility on how national rare diseases organisations or alliances are defined; still, RDI aims to empower patients in their ability to lead their national organisations, now as in the long term.
- Must demonstrate political independence and minimize the risk of conflict of interest through transparency of financial information and diversified funding.

4.3 RDI Associate Members

4.3.a Criteria for Associate Membership

Umbrella organisations that do not meet all the above rules can apply for associate membership. Associate members can be, but are not limited to:

- Rare disease patient organisations which have less than one year of existence.
- International patient federations of a common disease that might include rare diseases.
- Patient organisations representing one rare disease or family of diseases in countries where there is no National Alliance to represent them
- Patient organisations that represent one disease or family of diseases in one country but have proven links with similar patient organisations in at least 3 other countries and have the intention to working to become an international federation or network.
- Non patient-driven organisations or professional organisations or other type of entity active in the rare disease field and contributing to the objectives of RDI by their mission and work;
- Pharmaceutical or biotech companies cannot be Associate members but other for-profit organisations might be eligible.

Associate members cannot be elected to the Council of RDI.

4.4 Membership Application

In order to become a member of RDI, the applying Organisation must complete a membership application form available from RDI. It must present on and with this form any information requested. It must do its best effort from the initial application to show how it fits the criteria.

The RDI Secretariat review the information submitted, liaise with applicant if necessary and validate the application for submission to the Council.

4.5 Assessment and Approval of Membership Applications

Upon submission of an application in the required form to RDI, the review is being performed by the Council according to the membership criteria in these By-Laws. One, or all, of these criteria could be waived in exceptional cases, due to the particularity of patient-driven organisations, rare diseases or contextual reasons.

The Council of RDI makes the final decision regarding membership, and is not obliged to disclose the reasons of this internal decision. The time between the validation of an application and Council's decision is usually thirty (30) days and can be extended for further information and analysis. If approved, the applicant organisation shall be notified in writing.

4.6 Membership Dues

Membership dues will be voluntary for the first year of membership. Membership dues will be mandatory thereafter. Dues are proportionate to the capacities of the Members, based on the annual budget of the Member in the previous fiscal year, determined from the documents submitted with the application.

The Council will decide on amounts and levels and these will be made available to members and applicants as well as on the website. Waiver of dues may be granted on a case-by-case basis as determined by the Council.

4.7 Membership Voluntary Contributions

Members are invited to provide additional financial contributions to the core budget of RDI or to a specific programme (e.g. Membership Meeting, Fellowships, Document).

Members active participation as volunteers or for in-kind services provided are recognised through an economic worth valorisation. This economic valorisation is conducted by the RDI Secretariat and validated by the member. These valorisations are included in the budget and financial report. The valorisation method follows a written procedure and is controlled by the external Auditors.

The time spent by members of Council performing Council duties cannot be counted as economic valorisation and cannot be included in the budget.

4.8 Membership Benefits

These benefits may change over time, at the discretion of the Council. At the time of adoption all members, full or associate, shall benefit from the following:

- Are entitled to use the RDI logo “Member of Rare Diseases International”;
- Are listed on RDI website, annual report, public documents, position papers;
- Can apply to all Call for Expression of Interest for possible appointment by the Council in all RDI committees or working group;
- Are consulted on the By Laws, the Annual Work Programme and major Positions
- Attend the Membership Meetings;
- Access exclusive resources such as RDI webinars, RareConnect RDI community or Policy events;
- Network and collaborate with peer organisations, to learn from each other and advocate together for bigger impact;
- Enhance their capacities to influence global policies e.g. health and disability, by accessing the United Nations, the World Health Organisation, and other international bodies, while interacting with influential actors in development policy, human rights, etc;
- Directly influence and partner with the rare diseases stakeholders acting at global level in biomedical research, information, health industry, national policies

4.9 Termination of Membership

A membership in the Organisation is terminated when:

- (a) the member resigns;
- (b) the member is not paying its membership dues;
- (c) the member is expelled or their membership is otherwise terminated in accordance with the articles or by-laws;
- (d) the Member Organisation is liquidated and dissolved.

4.10 Resignation

Any Member shall advise, by written notice to RDI, of its decision to withdraw as a Member. Said written notice of withdrawal shall be effective upon receipt. Such resignation shall not relieve the Member so resigning of the obligation to pay current dues, or other charges theretofore accrued and unpaid nor entitle such member to a refund of any dues or other charges previously paid.

4.11 Discipline of Members

The Council shall have the authority to suspend or expel any member from the Organisation for any one or more of the following grounds:

- violating any provision of the articles, by-laws, or written policies of the Organisation;
- carrying out any conduct which may be detrimental to the Organisation as determined by the Council in its sole discretion;
- for any other reason that the Council in its sole and absolute discretion considers to be reasonable, having regard to the purpose of the Organisation.

In the event that the council determines that a member should be expelled or suspended from membership in the Organisation, the Chair, or such other officer as may be designated by the Council, shall provide thirty (30) days' notice of suspension or expulsion to the member and shall provide reasons for the proposed suspension or expulsion. The member may make written submissions to the Chair, or such other officer as may be designated by the Council, in response to the notice received within such thirty (30) day period. In the event that no written submissions are received the Chair, or such other officer as may be designated by the council, may proceed to notify the member that the member is suspended or expelled from membership in the Organisation. If written submissions are received in accordance with this section, the council will consider such submissions in arriving at a final decision and shall notify the member concerning such final decision within a further thirty (30) days from the date of receipt of the submissions. The Council's decision shall be final and binding on the member, without any further right of appeal.

ARTICLE 5 – ANNUAL MEETING OF MEMBERS: RDI MEMBERSHIP MEETING

An Annual Meeting 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. Such meetings shall be held for the purpose of gathering RDI Members, discussing actions and orientations, networking peer to peer and with partners.

5.1 – RDI Membership Meeting agenda:

The agenda will usually be organised in two parts: the Annual Business Meeting of Members and the Programme Agenda of the Membership Meeting.

The Business Agenda of the Annual Meeting of Members include:

- Adoption of the Agenda
- Presentation and adoption of annual Activity Report
- Presentation and adoption of annual Work Programme; the annual Work Programme consist of an Action Plan, a Budget, an Organisation Chart, a tentative annual calendar
- Election of members of the Council
- Adoption of resolutions

The Programme Agenda of the Membership Meeting may include:

- Discussion of the RDI strategy and of the rare disease strategy at global and national levels,
- Common positions of the RDI members
- Exchange of experience to build capacities at national and international levels

The Membership Meeting Agenda is prepared by the Council. The Council may involve other members to develop the program meeting.

5.2.a – Notice & Minutes of Membership Meetings

Written notice stating the place, day and hour of any Annual Meeting of the Members shall be provided to each Member entitled to attend and vote at such meeting, by the Secretary, no less than sixty (60) days before the date of such meeting, by the Council. Such written notice shall be provided by surface mail or electronic means. Those receiving the notice will also receive an Agenda of the meeting and all relevant documents for adoption.

Minutes of Annual Business Meeting of the Members will be approved by the Council and sent to all members within sixty (60) days following the meeting.

There are no minutes for the Program Agenda of the Membership Meeting, but a synthesis may be sent to all members.

5.3.b – Consultation method, Quorum, Voting, Majority and Proxies for the Annual Meeting of Members

Consultation. The Business agenda of the Membership Meeting can be organised face to face or by electronic means or a blend of both, aiming to consult as many members as possible.

Quorum and Votes. There is no quorum for the Annual Meeting of Members. 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.

Majority. On Business Agenda items, votes are on ordinary resolutions and as such counted by simple majority. On other Agenda items, consensus amongst all RDI members shall be seek whenever possible; if no consensus can be reached on a particular matter, the issue will be submitted to vote and the majority of those Members attending the meeting either in person or by electronic means, will decide of the outcome.

Proxies. Every Member entitled to vote at meetings of the Members shall, in the notice calling the meeting, receive a reminder of the existence of the proxy right described in this

paragraph and may, by a Proxy, appoint a Proxy Holder from among the membership, to attend and act at the meeting in the same manner, and to the same extent and with the same power as if the Member were present at the meeting. The Proxy shall cease to be valid upon the adjournment of the Meeting. Each Proxy Holder must be a Member of the Organisation. No Proxy Holder may hold more than five proxy votes to be cast at the meeting.

ARTICLE 6 – PARTNERS

The objectives and scope of the cooperation will be defined by separate Letter of Agreements / Memorandum of Understanding between RDI and the Partner. Examples of organisations with which RDI would have an interest to partner include: ICORD, IRDiRC, ORPHANET, IFPMA and learned or scientific societies e.g. the International Society of Human Genetics, international societies of medical specialists or nurses or social workers.

ARTICLE 7 – GOVERNING COUNCIL: THE COUNCIL

7.1 Responsibilities

The Organisation shall be governed by a Governing Council, known as the Council. The Council shall establish policies and directives governing business and programs of Organisation and shall delegate to any current or future RDI Secretariat and Organisation staff, subject to the provisions of these Bylaws, authority and responsibility to see that the policies and directives are appropriately followed.

Additional responsibilities of the Council include:

- Directing RDI towards its Mission and Vision, and will ensure that RDI has a long term strategy to achieve its objectives;
- Ensuring the good governance of RDI and high involvement of its members;
- Ensuring that material or immaterial assets of RDI are effectively managed;
- Assessment and decision on membership applications;
- Preparation of the annual work program, organisation of the Membership Meetings, definition of the terms of reference, appointment of members to Committees and working groups, and organisation of capacity building and advocacy activities to meet the expectations of RDI members.

7.2. Qualifications

All Directors are required to be fluent in English, both spoken and written; and have personal or professional knowledge or association with rare diseases with a robust experience in working

with patients / patient groups as well as in advocating for rare diseases at national or international levels. All Directors must have an ability to work across cultures and in a team spirit.

All Directors are required to be able to commit time to RDI activities, to prepare the meetings, to participate in monthly teleconferences and to take part in the Membership Meetings. At least an equivalent of 12 full days per year is expected.

7.3 Number

Members of the Governing Council shall consist of not less than five (5) and no more than nine (9) Directors. The number of Members may be changed by vote of a majority of the entire Council, but no decrease may shorten the term of any incumbent Director. Each Full Member of RDI may submit a nomination of an individual representative of their Organisation to serve on the Council. Full Member may only submit one (1) nomination of an individual representative per election. Only Full Members of RDI have the right to participate in the election of Council Directors. No RDI member Organisation can have more than one representative on the Council at any given time. Council Directors do not have any alternates. Council members who cannot participate in any specific meeting or activity may not designate someone else to fulfil their role or obligation.

7.4 Terms

Each Director shall be elected for a term of three (3) years, except for the first election, where elected candidates will serve terms of three (3) years, (2) two years and one (1) year, with higher number of years allocated to candidates receiving higher number of votes. Every year 2 or 3 Directors on the Council will stand for re-election. Two (2) elected candidates will stand down by rotation for two of these years and three (3) in the other. This would then result in regular terms of three years thereafter.

Outgoing Directors on the Council are eligible to be nominated by their Organisation for re-election.

7.5 Resignation

While Directors are nominated by their member Organisations they are elected as individuals. The member Organisation may not, prior to the end of the Council Director's term, substitute another representative for the individual elected. Moreover, the elected Council Director will relinquish his/her membership in the Council for any of the following reasons (1) the individual is no longer recognized as a representative by the RDI member; (2) the Organisation's RDI membership is discontinued; or (3) the individual leaves the Council for any other reason. In the event that a Director wishes to resign, they may do so by filing a written resignation with the Secretary of the Organisation.

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.

7.6 Removal

Any Director may be removed, with cause, by a two-thirds vote of the remaining Directors. A Director on the Council may be removed if one or more of the following conditions have been met:

- The Director has unjustified absences from three consecutive Council meetings
- The Director has not met their responsibilities as a Director of the Council or appears not to meet the required qualifications
- The Director has acted in violation of the By Laws

7.7 Vacancies

In the case of a vacancy prior to the end of term, the position will be filled for the remainder of that three-year term at the next election. At the next election, the individual winning candidate receiving the lowest number of votes will be designated to fulfil the uncompleted term.

7.8 Elections

Elections will be held every year, except for the first election, where candidates will serve terms of three, two and one years, with higher number of years allocated to candidates that received higher number of votes in the election

7.9 Council's Meetings

The Council will meet four 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. If an annual RDI Membership Meeting is to be held the Council will convene separately at that time for at least half a day but up to a full day.

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.

Agendas and Table of Actions & Decisions are widely available to members. Documents are provided widely or on request.

7.10 Action Without Meeting

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. Quorum and majority rules are the same as in duly called meetings. These decisions are recorded in the next Table of Actions and Decisions.

7.11 Quorum

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.

7.12 Voting Rules

When votes are necessary, the rule is a simple majority. In case of split vote, the Chair has the pre-eminence.

7.13 Attendance

Directors are expected to attend all meetings. Apologies are accepted in writing and the absence is accepted and noted in the minutes of the Council meeting. Unjustified absence from three consecutive meetings can result in a removal from the Council.

7.14 Compensation

Directors on the Council shall not receive any compensation or fees for serving as a Director, but nothing herein contained shall be construed to preclude any Director from receiving reasonable reimbursement for expenses incurred by or on behalf of the Organisation.

ARTICLE 8 - OFFICERS

8.1 Number and Qualifications

The Officers of the Organisation shall consist of the elected officers, namely Chair, Secretary and Treasurer. The Council may need to consider having other Officers such as Vice Chair. No person may hold more than one office in the Organisation concurrently.

8.2. Election and Term of an RDI Officer

The officers shall be elected by and from the Governing Council for a term of one year. Officers may be re-elected to the same position. Rotation is encouraged.

8.3 Removal

Any officer elected by the Governing Council may be removed by the Council with or without cause. A vacancy in any office occurring for any reason, including the removal of an officer, may be filled for the unexpired portion of the vacated officer's term by the Governing Council.

If an officer is unable to perform their duties for any reason for a period longer than 90 days the Executive member shall stand down from the position and the council may appoint someone from within the council to take on those responsibilities for the remainder of the term of office. The Executive member standing down from office shall remain a council member for the remainder of their term unless he/she decides to retire from the council.

In the case of the Chair, the Secretary ensures the interim until a new Chair is being elected for the remainder of the term of office.

8.4 Description of Officers

The officers must be Directors and shall have the following duties and powers associated with their positions:

- (a) **Chair of the Council** –The chair of the council, shall, when present, preside at all meetings of the Council of directors and of the members. The chair decides on the agenda of all meetings of the Council of directors and of the members, as much as possible in consultation with the other directors. The chair shall have such other duties and powers as the council may specify.
- (b) **Vice-Chair of the Council** – If one is to be appointed, and if the chair of the council is absent or is unable or refuses to act, the vice-chair of the council, if any, shall, when present, preside at all meetings of the council of directors and of the members. The vice-chair shall have such other duties and powers as the chair may specify.
- (c) **Secretary** – The secretary shall attend and be the secretary of all meetings of the council, members of the council. The secretary shall enter or cause to be entered in the Organisation's book, the Organisation By Laws and procedures, the minutes of the Annual Meeting of Members and possible synthesis of the Membership Meeting programme, the Table of Action & Decisions of the Council's meetings, the Letters of Agreement / Memorandum of Understanding. The secretary shall give, or cause to be given, as and when instructed, notices to members, directors, the public accountant and members of committees. The secretary shall be the custodian of all books, papers, records, documents and other instruments belonging to the Organisation which will be maintained at the RDI office.
- (d) **Treasurer** – The treasurer shall have such powers and duties as the council may specify. The treasurer will prepare the annual budget, follow up the execution of the budget, validate the

financial report, plan a multiyear budget, support the resource development, plan and take action is the support of the sustainability of the Organisation, ensure financial and legal decision making process are respected.

ARTICLE 9 – COMMITTEES AND WORKING GROUPS

9.1 Committees – The Governing Council can establish Committees. In addition to the standing committees the Council may also establish Working Groups as deemed necessary.

9.2 Finance & Sustainability Committee – The Finance Committee shall consist of the Treasurer as Chair, and at least two (2) additional members, which can be directors or not. Subject to the Council, this Committee shall have charge of and be held responsible for overseeing and approving all financial planning for the Organisation, including the annual budget, the pluri-annual budget, the short term and medium term resource development actions to ensure RDI takes actions to develop its own resources, as well as the planning for a long term sustainability.

9.3 Advocacy Committee – The Advocacy Committee shall consist of:

- A Chair;
- At least two (2) directors from the Council appointed by the Council, up to all directors in the Council;
- Up to 5 patient advocates appointed by RDI Council based on, a Call for Expression of Interest sent to all members;
- Other persons as approved by the Council which can be public affair staff from RDI member organisations and other patient advocates recognised for their expertise.

Members of the Committee commit and are required to take an active part in the Committee, to go through the RDI Secretariat before accepting any invitation to speak or represent RDI, to send an informative short report to be disseminated to the Committee and the Council, and available to members at large.

The Advocacy Committee shall be responsible for developing and recommending priorities, initiatives and policies for the Organisation; for preparing position papers or statements or declaration, as well as to review any position, statement, declaration of petition considered for endorsement by the Organisation.

9.4 Working Groups

The Chair and/or Council may at any time and from time to time create 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 Organisation.

The following are provided as a starting point to illustrate the intent and will evolve according to the needs of the Organisation:

- Working Group on RDI Strategy with the United Nation System
- Working Group on Research: The Working Group on Research will be responsible for feeding RDI's position on research and steering all research-related activities of the Organisation, including links with IRDiRC and BlackSwan Foundation.
- Working Group on the State of the Art of Rare Diseases in the World: The Working Group on the State of the Art is composed of representatives of RDI members from the first countries covered in the pilot extension of the State of the Art of Rare Diseases in the World
- Working Group on Pilot Countries for National Policy Enhancement
- Working Group on Building National Capacities around the World for a Specific Disease
- Working Group on Innovative Health & Social Services

9.5 Organisation of Committees and Working Groups

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 Chairs of all Standing Committees shall preferably be a Director so to ensure easy coordination with the Council. Committee Members may be full or associate members; members are appointed based on a Call for Expression of Interest, for equal opportunity to participate or the Council appoints the members of the Committees and Working Groups

Committees and Working Groups, their purpose and members, will be listed on the RDI website.

Committees and Working Groups shall strive to achieve consensus. If a vote is necessary, a majority of the members of the Committee shall constitute a quorum, and a simple majority vote shall constitute the decision of the Committee.

9.6 Meetings

A committee meeting may be called by its Chair or by at least two members with prior notice. The Committees shall meet at least four (4) times per year in person or by teleconference, videoconference, internet or similar communications by means of which all participants can hear

each other at the discretion of the committee. Written short minutes shall be kept of all meetings and sent to the RDI Secretariat.

ARTICLE 10 – FINANCIALS

The fiscal year for the Organisation shall be from January 1 through December 31.

10.1 Empowerment on budget preparation and decisions

As of 2017, the budget's preparation of RDI will be performed by EURORDIS in conjunction with the Council when drafting the RDI annual Work Programme. The budget will cover a two years' period in order to give more visibility for the fundraising. The size of the budget will be estimated based on the potential contributions by members of RDI as well as on external resources secured or to be raised. The expenses shall be in correspondence with the priorities of the action plan.

A risk analysis will be prepared in conjunction with the budget. The expenses will be sorted out in two categories: committed and provisional; committed expenses can be engaged right from the start of the year; provisional expenses can be engaged when the corresponding resource is actually secured. The revenues will be sorted out in four categories: contract, ongoing, challenge and provision.

The council adopts the budget of the following years in November. In March, a revised version of the budget is adopted by the council before its adoption by the members. The budget is formally voted by the following annual meeting of members. In July, the budget is revised when necessary. This timeline is indicative and can be adjusted.

10.2 Financial and legal support services

EURORDIS, being legally and financially liable for RDI, shall have the final decision making power with regard to all financial and legal issues and may accept or refuse recommendations from the RDI Council on these matters.

The engagement of expenses and signature of contracts will be managed by EURORDIS staff upon instructions of RDI (e.g. chair, treasurer or a person delegated).

EURORDIS will not make legal or financial commitments impacting RDI without its consent.

The financial and support services unit of EURORDIS will have the duty to manage the financial books, treasury, validation of orders of payment as well as management of the financial risk.

Monthly budget follow-up showing the actual expenses and revenues as well as year-end forecast versus the budget will be sent before the 15th of the next month, including a detailed ledger of all expenses and income since the beginning of the year.

At the end of the year, a first draft of closing accounts will be sent before the 15th of January. The closed accounts are signed by the Finance Director of EURORDIS and the Treasurer of RDI sent to the Council before the last day of February.

RDI accounts are audited by an external Auditor firm as part of the annual audit of EURORDIS.

10.3 Resource development and financial sustainability

The Council is responsible for the development and diversification of RDI resources engaging both its members and external public and private resources, aiming to establish its long term sustainability, credibility and political independence.

The council will set, define and decide its strategy and action to develop these resources in coordination with the members of RDI.

ARTICLE 11 – CONTRACTS AND COMMITMENTS

11.1 Contracts

All contracts on behalf of RDI are to be authorized by majority vote of the Council and signed by a legal representative of EURORDIS. No individual member of the Council shall be authorized to sign any contract or agreement on the Organisation's behalf – except if duly authorized with an explicit written delegation.

11.2 Commitments

Commitments surrounding the Organisation's engagement, involvement, or participation in a program, service, event, or other activity as deemed appropriate by the Council is determined by the Council.

ARTICLE 12 – INDEMNITY AND INSURANCE

EURORDIS will be responsible for Insurance of all volunteers in the context of their RDI activities. The cost of the insurance will be covered by the membership dues.

ARTICLE 13 – ADOPTION AND AMENDMENTS

13.1 Adoption

These By-Laws are adopted jointly by the Governing Council of RDI and the Board of Directors of EURORDIS. Before their adoption, all RDI members have been consulted based on draft By-Laws. A formal adoption by vote of ordinary resolution by all members will be organised at the next Annual Meeting of Members of RDI.

13.2 Adoption of Amendments

The power to alter, amend, or repeal the Bylaws or adopt new Bylaws shall be vested in the Council with a two-thirds vote of the Directors. Each Amendment to these Bylaws shall first be approved by the Council second by EURORDIS' Board, prior to being effective for any purpose. RDI Members will be informed diligently and consulted at the appreciation of the Council; in all cases, the amendments are indicated at the next Annual Meeting of Members.

ARTICLE 14 – LEGAL INCORPORATION OF THE ORGANISATION

14.1 A legal incorporation of RDI can be decided by its members.

14.2 At the request of the Council, the Chair will call for a Special Meeting of Full Members to decide on the legal incorporation and adopt its Statutes of Incorporation.

14.3 To bring a Special Resolution to vote, it must be signed by at least one-fourth (25%) of the full members.

14.4 The quorum for voting on a Special Resolution shall be half of the full membership; in other words, to be legitimate, at least half of the full members need to cast a vote on a Special Resolution, either in person at a special meeting or by electronic means.

14.5 To pass, a Special Resolution requires a two third majority plus one of those casting a vote.

14.6 If and when such incorporation is envisaged, the RDI Council shall work closely with EURORDIS to ensure a smooth transition to the best respective interests of EURORDIS and RDI.

ARTICLE 15– CONFLICT OF INTEREST

Members of the Council of Directors shall scrupulously avoid any conflict between their respective individual interests and the interests of the Organisation in any and all actions taken by them on behalf of the Organisation. Any possible conflict of interest on the part of such person or persons shall be disclosed to the Chair of the Council and such person or persons shall abstain from voting. In addition, such interested Members must be absent – but listened to - during the Council vote on the decisions in question. The disclosure as well as the Governance Members abstention from voting shall be made a matter of record within the minutes of the appropriate meeting.

All candidates to the Council or to standing Committees (e.g. Finance or Advocacy) shall disclose their potential competing interest. A form for the Declaration of Potential Competing Interest will be provided by the RDI Secretariat. The fact of not providing a filled form will be a reason for not accepting the candidacy or to invalidate it.

ARTICLE 16 – NON-DISCRIMINATION POLICY

It shall be the Organisations policy to provide equal opportunity with respect to employment, volunteer participation, the provision of services and membership, irrespective of a person's race, colour, sex, age, ethnic origin, sexual orientation, religion, impairment, marital status, membership in any labour Organisation, political affiliation, and, for employment only, height, weight, and record of arrest without conviction.

ARTICLE 17 – SECRETARIAT

17.1 RDI members and its Council are supported by a Secretariat. The Secretariat is tasked by and report to the Council.

17.2 At the time of the adoption of these By Laws, the Secretariat is composed of only one person: the Rare Diseases International Senior Manager, based in Geneva. Other staff members may be recruited as permanent or temporary contract, as consultant or as intern, based on needs and according to resources, by the RDI Council.

17.3 RDI members may contribute to RDI Secretariat by allocating some of their staff members to specific responsibilities within the Secretariat, such as Finance, Website, Public Affairs, Communication & Media, Support of a specific Committee or Work Group

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