

# BYLAWS OF THE ASSOCIATION “INTERNATIONAL CONFERENCE ON RARE DISEASES AND ORPHAN DRUGS”

## CHAPTER I: GENERAL PROVISIONS

### **Article 1. Name**

1. Under the name "International Conference on Rare Diseases and Orphan Drugs», responding to the acronym ICORD, an Association, hereinafter "The Association", with legal personality, full capacity to act, and non-for-profit, is established under the rule of Organic Law 1/2002, of March 22, regulating the right of Association, and its complementary regulations.
2. For anything not covered in these Bylaws, the aforementioned Organic Law 1/2002, of March 22, and complementary development provisions shall apply.

### **Article 2. Duration.**

The Association is constituted for an indefinite time.

### **Article 3. Registered Office.**

1. The registered office of the Association is Passeig Vall d'Hebron 119-129 (Hospital Universitari Vall d'Hebron), Barcelona (08035), Spain.
2. The territorial scope of the Association will be both national and international.

### **Article 4. Aims**

The Association aims to improve the welfare of patients living with rare diseases and their families around the world through a better understanding of these diseases and the promotion of research, care, information, education and awareness.

### **Article 5. Activities**

For the fulfilment of the Aims specified in the preceding article, the Association may perform the following activities:

- a) Organize International Conferences on Rare Diseases and Orphan Drugs (hence the acronym “ICORD”).
- b) Promote the research, ethical practices, specific policies and actions related to rare diseases and orphan drugs in all regions of the world.
- c) Facilitate and provide a global forum for all stakeholders, in order to achieve effective communication, opinion-shaping and public debate on rare diseases and orphan drugs.
- d) Expand at an international level the debate, cooperation and coordination about research, policies and any other actions of all agencies and institutions active in the field of rare diseases and orphan drugs.

- e) Exchange good practices among agencies and existing entities, and develop international tools and approaches to address common problems around rare diseases and orphan drugs.

## **CHAPTER II: THE MEMBERS**

### **Article 6. Definitions and admission of Members**

1. Anyone with capacity to act who has an interest in the development of the Aims and Activities of the Association, and who meets the requirements established in any of the Members' types defined below, may become a member of the Association.
2. Within the Association, the following types of partners are established:
  - a) Full members  
Individuals whose activity is related to the field of rare diseases and orphan drugs, including healthcare professionals, researchers, teachers, professionals in the pharmaceutical and biotechnology sector, members of regulatory bodies, health authorities, public-policy makers and representatives of patient groups.
  - b) Honorary Members  
Individuals who have excelled in the field of rare diseases and who are retired from their usual activity, as well as distinguished individuals who, in the view of the Board, could be valuable members for the activities of the Association.
3. Additionally, the Association may designate Associated Members, who will be individuals involved in the field of rare diseases and orphan drugs, but which do not fulfil the requirements of Full Members' category, or legal entities with for- or not-for-profit activities related to rare diseases and orphan drugs (such as, for example: professional organizations, universities and other academic institutions, hospitals and clinics, patient organizations, groups for the defense of consumers or trade associations).

### **Article 7. Appointment of Members**

1. Individuals interested in joining the Association shall send to the Secretary of the Association a duly completed membership application form for its consideration by the Board.
2. The Board shall be the competent body to accept or reject the members, upon verification of the compliance with the moral, ethical and professional qualifications requirements established in Article 6.
3. For Honorary Members, their acceptance or conversion from a Full Member status shall be proposed by a Full Member to the Board, which shall verify compliance with the relevant requirements; in this case, its ratification will be competence of the General Assembly.

### **Article 8. Membership Termination**

1. A Member may renounce to such condition by means of a written request to the Board.

2. Membership can also be cancelled due to the following reasons:
  - a) Nonpayment of dues for two consecutive years;
  - b) Failure to continue to comply with the requirements which justified its acceptance as a Member; and,
  - c) Unethical or unprofessional conduct of the Member in question.
3. Termination of membership for any of the reasons referred to in paragraph 2 shall be agreed upon by the Board.

**Article 9. Rights.**

1. Full Members shall have the following Rights:
  - a) Take part in all activities organized by the Association in order to fulfil its Aims.
  - b) Enjoy all the advantages and benefits that the Association may obtain.
  - c) Participate in the meetings of the General Assembly with voice and vote.
  - d) Be electors and eligible for elected positions of the Association.
  - e) Be informed of all decisions adopted by the management bodies of the Association.
  - f) Make suggestions to the members of the Board in order to better accomplish the Aims of the Association.
  - g) Receive all communications and publications of the Association.
2. Honorary Members shall have the following Rights:
  - a) Take part in all activities organized by the Association in order to fulfil its Aims.
  - b) Enjoy all the advantages and benefits that the Association may obtain.
  - c) Participate in the meetings of the General Assembly with voice and vote.
  - d) Be electors and eligible for elected positions of the Association.
  - e) Be informed of all decisions adopted by the management bodies of the Association.
  - f) Make suggestions to the members of the Board in order to better accomplish the Aims of the Association.
3. Associated Members shall have the following Rights:
  - a) Take part in all activities organized by the Association in order to fulfil its Aims.
  - b) Enjoy all the advantages and benefits that the Association may obtain, although they will not be eligible for the Board.
  - c) Participate in the meetings of the General Assembly with voice but without vote.
  - d) Be informed of all decisions adopted by the management bodies of the Association.
  - e) Make suggestions to the members of the Board in order to better accomplish the Aims of the Association.
  - f) Receive all communications and publications of the Association.

**Article 10. Duties.**

1. Full Members shall have the following Duties:
  - a) Comply with these Bylaws and valid agreements of the General Assembly and the Board.
  - b) Pay the established fees.
  - c) Carry out the duties associated with any position they may hold, if so elected, in the Association.
2. Honorary Members shall have the following Duties:
  - a) Comply with these By-Laws and valid agreements of the General Assembly and the Board.
  - b) Carry out the duties associated with any position they may hold, if so elected, in the Association.
3. Associated Members shall have the following Duties:
  - a) Comply with these By-Laws and valid agreements of the General Assembly and the Board.
  - b) Pay the established fees.
4. All Members shall communicate to the Secretary the email address where they wish to receive Assembly calls and all other correspondence from the Association.

**CHAPTER III: THE GENERAL ASSEMBLY**

**Article 11. Composition and Functions.**

1. The General Assembly is the supreme governing body of the Association and shall be composed of all the Members, Ordinary, Honor and Associated Collaborators.
2. The General Assembly has the following Functions:
  - a) Approve the Board's overall management performance.
  - b) Evaluate and approve the Association's annual accounts and budget for the following financial year.
  - c) Elect the members of the Board and auditors.
  - d) Establish the membership fees.
  - e) Approve the dissolution of the Association.
  - f) To alienate or dispose of property.
  - g) Any other competence that is not attributed to other Association bodies.
3. Meetings of the General Assembly can be ordinary or extraordinary. The Association will hold at least one regular session of the General Assembly during each calendar year, preferably in person, but can take place on-line if circumstances prevent or hinder face-to-face meetings. Extraordinary meetings may convene and celebrate, upon proposal from the Board, when the circumstances warrant it or when an amendment of statutes, including the change of registered office has been proposed. Similarly to ordinary meetings, these can take place on-line if circumstances require it.

**Article 12. Call of the General Assembly.**

1. Calls of the General Assembly will be issued by the President or, alternatively, by the Secretary, and will be done in writing, through any legally admissible media, stating the day and UTC hour of the meeting, as well as the agenda with a detailed list of the issues to be addressed. In case of in person meetings, the venue will also be stated. Alternatively, on-line access data shall be provided.
2. Calls will be addressed to all Members, whether Full, Honorary or Associated, although the latter do not have the right to vote. The Board shall be empowered to invite third parties or entities to meetings of the General Assembly, on an isolated or regular basis.
3. Calls of ordinary meetings must be issued at least three (3) months in advance, and may also state, if applicable, the date and UTC time at which the General Assembly will meet on second instance; the time between first and second instance cannot be less than thirty minutes.

The agenda of the ordinary General Assembly shall include the following items: opening of the meeting; Secretary's report, including presentation and approval of the previous Assembly Minutes; President's report, Treasurer's Report; the Auditors' report ; approval, where appropriate, of the general action plan of the Association; approval, if applicable, of the previous year accounts; approval, where appropriate, of the activity of the Board during the previous year; reports of the Commissions and working groups; new proposals; other items and closing of the meeting.

**Article 13. Quorum and Majorities at the General Assembly**

1. General Assembly meetings, whether ordinary or extraordinary, will be validly constituted on first call when attended, in person or on-line, by one-third of the Members with voting rights, and in second instance whatever the number of Members with voting rights.
2. Members may be represented at sessions of the General Assembly by another Member. The aforementioned representation must be conferred in writing, may indicate the sense of the vote in the session for which representation is granted and can be special for each session of the General Assembly.
3. Except in those matters for which a higher majority is required, agreements shall be made by simple majority of those participating, either directly or represented through written delegation , i.e., when the affirmative votes outweigh the negatives, not being computable for this purpose the null o blank votes nor the abstentions.

**Article 14. Modification of the Bylaws**

1. The Board may suggest the revision of the Bylaws, by means of a specific proposal to this end, which must be joined to the General Assembly call.
2. Additionally, and irrespective of any proposal from the Board in this regard, any Full or Honorary Member may propose the revision of the Association Bylaws. Proposals for revision must be submitted to the Secretary of the Association at least two (2) months before the date of the General Assembly meeting.
3. Proposals for revision of the Bylaws made by Full Members shall be sent to the Board, which may make recommendations in this regard.

4. These proposals, together with the recommendations of the Board, will be distributed to all Members at least one (1) month prior to the date of the General Assembly meeting.
5. Modification of the Bylaws shall require the approval of the General Assembly by a majority of two thirds (2/3) of the members with voting rights present at the meeting.

#### CHAPTER IV: THE EXECUTIVE BOARD

##### **Article 15. Functions of the Board.**

1. The Executive Board (herein referred to as the "Board") is the body responsible to direct, manage, administer and represent the Association. Its powers shall extend, in general, to all acts pertaining to the Aims of the Association, provided that they do not require, in accordance with these Bylaws, previous authorization from the General Assembly.
2. Specific powers of the Board are:
  - a) Direct the social activities and economic management and administration of the Association, carrying out the appropriate contracts and acts.
  - b) Execute the agreements of the General Assembly.
  - c) Formulate and submit to the approval of the General Assembly balance sheets and annual accounts, as well as the budget for the following financial year.
  - d) Decide upon the admission of new members.
  - e) Appoint delegates for any particular activity of the Association.
  - f) Decide if the format of General Assembly meeting will be in person or on/line, based on the current and/or foreseeable circumstances at the scheduled date of the meeting.
  - g) Any other capacity which is not the exclusive competence of the General Assembly.

##### **Article 16. Composition of the Board**

1. The Board shall be formed by official members and members-at-large.
2. The official members will be:
  - a) The President
  - b) The President-elect
  - c) The Past-President (immediately prior to the current President)
  - d) The Secretary
  - e) The Treasurer
3. The rest of the members of the Board of Directors shall be four (4) to eight (8) Members-at-Large, or another number as decided by the General Assembly, which shall be elected by the Assembly General among Full- o Honorary Members volunteering to that effect, and duly representing each of the professional profiles defined in Article 6, point 2.
4. Any Full Member, as long as is up to date in the payment of fees, or Honorary Member may become a member of the Board.

5. The members of the Board shall be appointed by the General Assembly, with the exception of the President and Past-President. Their election shall take place at the first ordinary meeting of the General Assembly of the last year of mandate of the current member(s), or upon their eventual resignation.
6. All members of the Board of Directors shall serve without financial compensation.
7. The mandate of the members of the Board shall be two (2) years, extendable for a single second consecutive term of identical duration. Upon completion of their mandate, if a substitute has not yet been elected by the General Assembly, they will continue to hold their position(s) *ad interim* until the new Board members are elected.
8. The members of the Board may cease in their role by voluntary resignation, communicated in writing to the Board, or for breach of their mandated obligations. Vacancies occurring on these grounds shall be temporarily filled by other members of the Board until their replacement by the General Assembly.

#### **Article 17. Operation of the Board**

1. The Board shall meet at least once a year, as well as at the request of its President, on its own initiative or at the request of half of its members.
2. Calls for Board meetings shall be made by the President and in writing, by any means of communication admissible in Law, expressing the day and UTC hour of the meeting, as well as the agenda, with a detailed list of the issues to be addressed. For in person meetings, the venue will also be stated. Alternatively, on-line access data shall be provided. However, requests can always be sent by email.
3. The sessions of the Board of Directors may be held via tele- or multi-conference.
4. Agreements on the Board of Directors shall be adopted by simple majority of votes. In case of tie, the vote of the President will be decisive.
5. The Board may decide to invite people to its meetings, whether they are Members or individuals external to the Association. These individuals shall have the right to attend the meeting with voice but without vote.

### CHAPTER V: OFFICIAL MEMBERS

#### **Article 18. The President.**

1. The President of the Board shall be a Full or Honorary Member who is a professional with active involvement in the field of patient care, teaching or research on rare diseases, or who performs its activity in some institution related to rare diseases and orphan drugs, or the representative of a patients' Association.
2. The President, who will serve as President-elect during the first two (2) years, shall be elected by the General Assembly. After these two years, the President-elect shall assume the Presidency for another two (2) years, and may not be re-elected for a second consecutive term. This election will be held in the first ordinary meeting of the General Assembly during the last year of mandate of the current President.
3. At the end of the current President's mandate, if a President-elect has not been appointed by the General Assembly, the President will continue *ad interim* until the acceptance as President of a new President-elect.

4. The President shall have the following powers:
  - a) Legally represent the Association in front of all public or private organizations, as well as the media;
  - b) Convene and preside the sessions of the General Assembly and the Board, as well as moderate their debates;
  - c) Create Committees, other than the Standing ones already defined in these statutes, and propose all of its members;
  - d) Sign collaboration agreements with other entities;
  - e) Order payments and sign contracts and financial instruments on behalf of the Association, in accordance with the procedures laid down in article 22;
  - f) Adopt any urgent measure necessary or desirable for the smooth running of the Association, although they must be subsequently reported to the Board.

**Article 19. The Past-president**

1. Once expired the two (2) years term, the President shall automatically become Past-president for another two (2) years.
2. The Past-president will remain a member of the Board during the term of this position.

**Article 20. The President-elect**

1. The President-elect shall be elected by vote of the General Assembly. The election will take place first ordinary session of the General Assembly during the last year of the mandate of the current President-elect, i.e. prior to the assumption of the President position.
2. The President-elect, which shall become a member of the Board, will take effect when the current President-elect takes office as President. The President-elect shall hold this post for a period of two (2) years, after which shall assume the Presidency.

**Article 21. The Secretary.**

1. The Secretary shall be elected by the General Assembly for a period of two (2) years, extendable for a single consecutive term.
2. The Secretary shall take in charge the direction of the purely administrative tasks of the Association, shall issue certificates, act as bookkeeper of the Association legal books and Members' official directory, and guard the documentation of the entity, verifying the proper communications with respect to Board's appointments and filing of formal agreements in the corresponding Registries, as well as any other documentary legal obligations. The Secretary shall also take minutes of the General Assembly and Board meetings.
3. The Association may have a Technical Secretariat, who may be a natural or legal person that does not enjoy membership, to assist in the implementation of its activities. The Technical Secretariat shall be selected by the Board, and can assume the following functions:
  - a) Assist the President carry out the activities and contacts related to the Association.



- b) Assist the Secretary in the maintenance of the Members directory, the minutes' files, mandatory registrations and any other administrative tasks.
- c) Assist the Treasurer in the maintenance of the Association bookkeeping, arrange the collection of fees, if any, carry out recurrent payments related to the normal operation of the Association and any other administrative tasks.
- d) Assume the representation of the Association to sign contracts and instruments on behalf of the Association, as described in Articles 24.5 and 24.6.
- e) Assist the Strategy and Planning Commission in the organization of the annual meetings.

**Article 22. The Treasurer.**

1. The Treasurer shall be elected by the General Assembly for a period of two (2) years, extendable for a single consecutive term.
2. The Treasurer is responsible for all collections and payments made by the Association, always in compliance with the instructions of the Board. The Treasurer shall keep the necessary books for audit purposes, and shall inform the General Assembly and make any necessary recommendations in relation to the Economic Affairs the financial status of the Association to the Board.

**CHAPTER VI: FINANCES**

**Article 23. Heritage.**

1. The Association is constituted without any initial heritage or social fund.

**Article 24. Association Finances.**

1. The Association will be funded through fees paid by Members or by other sources of income authorized by the Board such as, for example, grants, donations, bequests or inheritances that may legally receive from Members or third parties, or any other lawful source of income.
2. Every year, during the ordinary General Assembly, the Treasurer shall submit to the Members an annual budget for the following year and the annual accounts of the previous year, for approval by this body.
3. The associative and economic exercise corresponds to the calendar year, so the start date will be January 1st and the closing date December 31st.
4. The accounts of the Association shall be audited by two (2) Full Members who will present their Report to the General Assembly. These Members shall be elected by the General Assembly for a two (2) year term, and may be elected for two additional terms.
5. The Treasurer, the President or a representative designated in writing by the Board may individually assume the representation of the Association in order to sign contracts and financial instruments on behalf of the Association for an amount up to three thousand euros (€3,000), or to make individual payments up to three thousand euros (€3,000).

6. The signing of contracts and financial instruments on behalf of the Association by an amount exceeding three thousand euros (€3,000), or disbursement of amounts exceeding three thousand euros (€3,000), shall require the joint signature of at least two of the following persons: the Treasurer, the President or a representative appointed specifically to this purpose by the Board.

The signing of such operations should correspond to initiatives or procedures previously agreed by the General Assembly and/or the Board. In any case, if the President and the Treasurer do not sign jointly, the non-signing Member must be informed prior to the signing and, if in disagreement, the signing must be previously ratified by the majority of the Board. In the absence of such ratification, the signatories will acquire the commitment on a strictly personal basis.

**Article 25. Fees.**

1. The Association may finance itself through the adoption of annual fees from its Members.
2. The annual fees shall be approved by the General Assembly, upon proposal of the Board.
3. The annual fee can be equal to zero.
4. Payment of annual fees shall be made effective before the ordinary General Assembly, unless the Board establishes a different date for a particular period.
5. If a Member does not fulfil the payment of fees for two consecutive years, his/her membership may be terminated, as stipulated in Article 8.

**CHAPTER VII: COMMITTEES**

**Article 26. Types of Committees.**

1. **Nominations Committee:** this Committee, composed of the last two Past-Presidents, the current President and the President-elect, who will preside over it, aims to provide to the Board a list of candidates to become members and auditors of such Board. Candidates must have expressed their willingness to take the positions should they be elected.
  - a) The Commission may propose more candidates than vacancies, so that these vacancies are filled through an election.
  - b) The list of candidates will be presented to the Board, at the latest, one (1) month prior to the next General Assembly.
  - c) The Commission will be responsible for presenting the list, once approved by the Board, and to organize the elections during the General Assembly.
2. **Strategy and Planning Committee:** this Committee shall be composed by the President, the Secretary, and representatives elected by the Board of Directors among the Members of the association whose residence is where the next annual meeting will be held or nearby. The President shall chair the Committee. The Commission shall be responsible for the planning of the meeting and present it to the Board for its approval. It shall organize and execute the approved program. Also, the Commission shall be responsible for planning, organizing and executing other

programs in which the Association may be officially involved. The Commission may, at its sole discretion, seek assistance from other people, who may or not be Members of the Association.

3. The President can create other committees as needed. The President shall propose the individuals who will be part of these committees, which must be approved by the Board.
4. The Board of Directors may establish internal rules of operation of these committees

## **CHAPTER VIII: DISSOLUTION**

### **Article 27. Dissolution and of any remaining funds.**

1. The Association shall be voluntarily dissolved when so agreed by an extraordinary General Assembly convened for that purpose by the Board of Directors.
2. The agreement of Dissolution of the Association shall require the approval of the General Assembly by a majority of two thirds (2/3) of the Members with voting rights present at the meeting.
3. In the event of Dissolution of the Association, a Settlement Committee shall be appointed. Once all debts have been paid, any remaining funds shall be allocated to one or more organizations, chosen by the Board, whose aims and objectives are in line with those of this Association and do not distort its non-for-profit nature.