



CONSTITUTION for the INTERNATIONAL CONFERENCE FOR RARE DISEASES AND ORPHAN DRUGS (ICORD)

Article I: Name

The name of the Society shall be the “International Conference for Rare Diseases and Orphan Drugs”, abbreviated ICORD. This is a non-profit organization. The Society shall be registered in Solna, Stockholm County, Sweden.

Article II: Mission

To improve the welfare of patients with rare diseases and their families world-wide through better knowledge, research, care, information, education and awareness.

Article III: Aims

1. To organize International Conferences on Rare Diseases and Orphan Drugs (ICORD)
2. To promote research, ethics, policies and actions on rare diseases and orphan products in all regions of the world
3. To facilitate and provide a global forum for all stakeholders for effective communication, formation of opinion and public debate, concerning rare diseases and orphan products
4. To enhance international discussion, cooperation and coordination of research, policies and actions of all bodies active in the field of rare diseases and orphan products
5. To exchange best practices between existing bodies and develop international approaches and tools to address common issues in rare diseases and orphan products

Article IV: Amendments and Revisions

1. Changes to the constitution may be made by an affirmative vote of two-thirds (2/3) of the members present at a general meeting of the Society, provided proposed changes have been submitted to the Board and circulated among the members at least one (1) month prior to the general meeting.
2. Proposed changes may originate with any ordinary member of the Society. They should be submitted to the Secretary at least two (2) months prior to the general meeting.
3. Changes properly proposed to the Board will be presented at the next general meeting with the recommendation of the Board.

Article V: Dissolution

1. Dissolution shall be proposed, processed, and voted on as for amendments and revisions, Article IV.
2. In a case of dissolution of the Society, any funds remaining after payment of all outstanding debts will be donated to one or more organizations, with aims and objectives consonant with those of the Society, to be selected by the Board.



BY-LAWS for the INTERNATIONAL CONFERENCE FOR RARE DISEASES AND ORPHAN DRUGS (ICORD)

The Society shall be governed and guided by the principles set forth in these By-Laws.

ARTICLE I: MEMBERSHIP

Section 1 - Definitions and eligibility

The membership of the Society shall consist of:

A. Ordinary Members

All individuals active in rare diseases and/or orphan drugs, including professionals in health care, research, academy, industry, regulatory authorities, health authorities, public policy, and representatives for patient groups. Ordinary members pay dues, may participate in all activities of the Society, may hold office, are eligible to vote and receive all communications and publications of the Society.

B. Associated Members

Individuals that are involved in rare diseases and orphan drugs but not eligible as Ordinary members as defined above. In addition, non-for-profit and for-profit organizations involved in rare diseases and orphan drugs may also be Associated members, such as professional organizations, universities and other academic institutions, hospitals and clinics, patient's advocacy groups, and industry trade organizations. Associated members enjoy all rights and privileges of Ordinary members and pay dues, and will receive all communications and publications of the Society but may not hold office or vote.

C. Honorary Members

Ordinary members who have retired from active involvement in the field and distinguished individuals who, in the view of the Board, will be valued members of the Society. Honorary members enjoy all rights and privileges of Ordinary members but do not pay dues and may not automatically receive all communications and publications of the Society.

Section 2 - Appointment of members and termination of membership

- A. A completed application for membership is to be sent to the Secretary of the Society for consideration by the Board. Applications are approved by the Board.
- B. The Executive Board of the Society shall be the sole judge of moral, ethical and professional qualifications required for election to or termination of membership.
- C. Honorary members must be proposed to the Board by an Ordinary member and accepted by the Board before ratification by the membership at an annual meeting.
- D. Membership shall be cancelled on request of the member or on the grounds of: 1) nonpayment of dues for two successive years, 2) unethical or unprofessional behavior by the member. Cancellation of membership must be submitted to the Board.

ARTICLE II: DUES

Section 1

- A. The annual dues shall be set by the Board and ratified by the General Assembly by a simple majority vote. The annual due may be zero. The annual dues for individual members, non-for-profit organizations and for-profit organizations may differ.
- B. The annual dues shall be due and payable at the time of the annual meeting or by the date fixed by the Board for the payment thereof.
- C. Membership may be cancelled for failure to pay dues as set forth in Article I.

ARTICLE III: OFFICERS OF THE SOCIETY

The officers of the Society shall be the president, the secretary, the treasurer and the immediate past-president and the president-elect. The offices of secretary and treasurer may be held by the same person. The President must be a health care professional active in patient care, education or research in rare diseases, a professional active in society authorities regarding rare diseases and orphan drugs, or a representative for patient organizations. All other officer positions (except President and President-Elect) are open to all stakeholders. The officers serve without financial compensation. Terms begin and end at the end of the General Assembly of the Society as the final item of business.



- A. **President** - Elected for a two-year term, and may not be re-elected for a consecutive term.
1. Presides over annual meetings, is chairperson of the Board, appoints all members of committees not otherwise defined herein, organizes the agendas for Board and annual meetings, co-signs contracts and financial instruments on behalf of the Society (as outlined in Article V, sections 4-5), and serves as an ex-officio member of all standing and ad hoc committees of the Society.
 2. Represents the Society in dealing with other organizations and media.
 3. Becomes a member of the Board as the immediate past-president for the two years immediately following his/her term of office.
 4. A member of the Board may act for the then president under the conditions of Article IV.1.B.
- B. **President-Elect** - Elected for a two-year term as president. Succeeds to that office at the end of the term of the then incumbent.
1. Becomes a member of the Board as the president-elect for the two years prior to assuming the presidency.
 2. Serves as chairperson of the nominating committee.
- C. **Secretary** - Elected for a two-year term with one additional term permitted by re-election. Is responsible for communication with members and minutes of all meetings, and is ex-officio member of all committees.
- D. **Treasurer** - Elected for a two-year term with one additional term permitted by re-election. Co-signs contracts and financial instruments on behalf of the Society, as outlined in Article V (sections 4-5). Is responsible for all receipts and disbursements of money subject to direction from the Board. Such records as are necessary for auditing purposes must be kept. Recommendations concerning financial matters and the financial status of the Society are reviewed with the Board annually or more often as needed.

ARTICLE IV: THE EXECUTIVE BOARD

Section 1

The executive board (herein referred to as the “Board”) is the governing body responsible for operating the Society. It is composed of the immediate past-president according to Article III.A.3., the president-elect according to Article III.B.1., the other officers, and four to eight Ordinary members-at-large, or another number as decided by the General Assembly, elected by the membership for a two-year term. The Board should try to have a balanced representation from all stakeholders. All members serve without financial compensation.

- A. The Board is required to meet no less than once each year, and it may enroll participation by others, without vote, as needed. The President has the deciding vote, if the vote is otherwise tied.
- B. If for any reason, as determined by the Board, the president is unable to carry out his/her duties, the past-president assumes the duties and responsibilities of the president.
- C. A Board member-at-large may serve two consecutive terms.
- D. The Board may decide to call in other individuals to the Board meetings, for the entire meeting or parts of the meeting.

ARTICLE V: FINANCES

Section 1 - Financing of the Society will come through membership fees and/or from other sources approved by the Board.

Section 2 - An annual budget and accounting of the previous year’s finances are to be presented by the treasurer to the membership at each annual meeting. The financial year is a calendar year starting January 1 and running to December 31.

Section 3 - The financial records will be audited on a yearly basis by two ordinary members serving as auditors and their audit shall be presented at each annual meeting. The auditors are elected at the annual meeting by the membership for a two-year term and may be elected for two additional terms.

Section 4 - Signing of contracts and financial instruments on behalf of the Society, as well as disbursements from the treasury, each representing less than €3,000, can be made by the treasurer, the president or one representative of the Secretariat designated in written by the Board.

Section 5 - Signing of contracts and financial instruments on behalf of the Society, as well as disbursements from the treasury, to a value in excess of €3,000 must be signed by two of the treasurer, the president and one representative of the Secretariat designated in written by the Board.



ARTICLE VI: COMMITTEES

Section 1

Standing Committees include the Nominating Committee and the Strategy & Planning Committee. The president may appoint other committees on an ad hoc basis. The president is responsible for all appointments to committees, with review by and approval of the Board, except as described below.

A. Nominating Committee - This committee, composed of the two most immediate past-presidents, and the president-elect (who will act as chairperson), shall be responsible for providing the Board with a slate of officers and candidates for at-large membership on the Board, and auditors, the nominees having established a willingness to serve if elected.

1. The committee may propose more candidates than the number of vacancies to be filled by election.
2. This slate must be presented to the Board no later than one (1) months prior to the upcoming relevant General Assembly.
3. The committee will be responsible for presentation of the slate, as approved by the Board, and for carrying out the election at the relevant General Assembly.
4. Elections for secretary and/or treasurer and the Board members-at-large shall be conducted at the meeting marking the beginning of the then-incumbents' last year in office.
5. Elections for president shall be conducted at the meeting marking the beginning of the last two (2) years in office of the then-incumbent president. The president-elect thereupon becomes a member of the Board according to Article III.B.1.

B. Strategy & Planning Committee - The president, secretary and local representative(s) chosen by the Board (members of the Society whose residence is in or near the site of an upcoming annual meeting) will act as a strategy & planning committee for the upcoming annual meeting. The president shall act as chairperson. The committee shall be responsible for planning the meeting and for presenting plans to the Board for approval. It will organize and execute the approved program. The committee will also be responsible for planning, organizing and executing other programs in which the Society is officially involved. The committee may recruit, at its discretion, assistance from others who may or may not be members of the Society.

ARTICLE VII: SECRETARIAT

Section 1

The Society may have a Secretariat to support its activities. The activities of the Secretariat are to assist ICORD in activities it is commissioned to by the Board. Its potential duties include to:

1. Assist the President in performing Society activities and contacts.
2. Assist the Secretary to maintain a directory of the Society members.
3. Assist the Treasurer in arranging membership fee payments, if there is such a membership fee.
4. Co-sign contracts and financial instruments on behalf of the Society, as outlined in Article V, sections 4.-5.
5. Assist the Strategy & Planning Committee in organizing the Annual Meetings.

ARTICLE VIII: ANNUAL MEETING AND GENERAL ASSEMBLY

Section 1

The Society will hold at least one general meeting each calendar year, the Annual Meeting, at which there will also be a General Assembly Business Meeting. The Board may decide, at its discretion, to arrange an additional general meeting with a General Assembly Business Meeting in case of urgent matters. The date of each general meeting should be announced with at least three (3) months notice, which is the responsibility of the Secretary.

Section 2

The General Assembly Business Meeting will include at least the following items: Opening of the meeting, Secretary's report including the minutes from previous meeting, approval of the minutes from previous meeting, President's report, Treasurer's report, Auditors' report, approval of the Treasurer's report, approval of the Board's last year at office, nominees and elections, committee reports, new business, other items, closing of the meeting.