



NGO COMMITTEE FOR
RARE DISEASES

By-Laws of the **NGO Committee for Rare Diseases** (UN, New York)

1. Name and Nature

- a. The "NGO Committee for Rare Diseases (UN, New York)" (hereafter referred to as "the Committee") shall hereby be constituted as a Substantive Committee¹ of the Conference of Non-Governmental Organizations (hereafter referred to as "CoNGO") in Consultative Relationship with the United Nations.
- b. The Committee shall be constituted within CoNGO as a Substantive Committee in New York.
- c. The present by-laws shall be tabled for ratification at, and if approved be effective as of, the inaugural global gathering to be held on 11 November 2016 at the United Nations in New York, United States of America.

2. Authority and Purpose

- a. The mission of the Committee shall be two-fold:
 1. to serve as a resource for information to all constituents within the United Nations system and their related bodies on the nature of rare diseases, but also on the issues, challenges and urgent unmet needs associated with them, particularly from a political, economic and social point of view;
 2. to encourage and support actions through the United Nations that shall contribute to elevating rare diseases to the status of global public health priority, and to advancing the cause of people living with rare diseases worldwide, with due consideration to aspects related to inequities in access to treatment and care.

¹ As per paragraphs 38 to 47 of the "Rules of the Conference of Non-Governmental Organizations in Consultative Relationship with the United Nations" (June 2014), last accessed December 2015 via the following link: http://ngocongo.org/pdf/CoNGO_RULES_2014.pdf



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- b. This mission shall be accomplished through various ways and means, some of which are listed below for indicative purposes, and without any form of exclusivity:
1. by serving as an open forum to collect, share and disseminate up-to-date information and research on the global dimensions of rare diseases from a holistic point of view, but also to raise the profile of people living with rare diseases worldwide, particularly through dedicated events (e.g. conferences, workshops, etc);
 2. by calling for and supporting the recognition of rare diseases as a priority in the areas of public health, research, medical care, social care and integration, both at the international and national levels;
 3. by highlighting current or potential opportunities for improved and more integrated collaborations or public-private partnerships between stakeholders, governmental or non-governmental alike, and particularly actual synergies with the work of other existing Substantive Committees within CoNGO;
 4. accordingly, by encouraging all relevant United Nations bodies – and firstly its Economic and Social Council (hereafter referred to as "ECOSOC") – to better reflect aspects related to rare diseases into their missions, strategic plans and ongoing activities, particularly with respect to policy areas such as disability, mental health, vulnerable populations, gender issues and human rights;
 5. by developing and presenting reports, recommendations for action and any other forms of position statements on rare diseases and associated issues to all relevant UN bodies and other international stakeholders as appropriate;
 6. by cooperating *bona fide* with those same stakeholders to ensure the said recommendations for action, resolutions and any other forms of position statements are properly considered and effectively translated into political action at the earliest opportunity.

3. Membership

a. **Regular Member:**

1. A representative of a non-profit, non-governmental organization in consultative status with ECOSOC and the mission and activities of which are fully relevant to the purpose of the Committee, to the exception of organizations referred to hereafter under point 3.d
2. Eligible to vote, both on the election of Officers and on regular business of the Committee itself; to hold office (i.e. to be elected as Officers of the Executive Board); and to chair any ad hoc committees or working groups that may be set up in the course of the Committee's activities

b. **Associate Member:**

1. A representative of a non-profit, non-governmental organization not currently in a consultative status with ECOSOC but in operational or regulated status with any other body within the United Nations System (e.g. WHO, UN Department of Public



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Information) and the mission and activities of which are fully relevant to the purpose of the Committee

2. Eligible to vote on regular business of the Committee itself only; to chair and sit on any ad hoc committees or working groups that may be set up in the course of the Committee's activities; but not to hold office
3. An organisation in the process of applying for consultative or equivalent status with a UN body may be *provisionally* eligible to Associate Membership upon submission of substantive proofs of its application, and for the limited period of time leading to a formal decision of the said UN body on its application. Associate Membership shall be confirmed or revoked upon receipt of such decision.

c. **Observer Member:**

1. A representative of a non-profit, non-governmental or governmental organisation, patient association, civil society organisation, academic institution or any other non-profit entity contributing by its mission and activities to the purposes of the Committee
2. Eligible to attend and contribute to regular meetings; to sit on any ad hoc committees or working groups that may be set up in the course of the Committee's activities; but not to vote; nor to hold office

d. **Supporting Member:**

1. A representative of a for-profit undertaking, or of a non-profit, non-governmental organization representing for-profit interests, that fully adheres to the purposes of the Committee
2. Eligible to attend and contribute to regular meetings; to sit on any ad hoc committees or working groups that may be set up in the course of the Committee's activities; but not to vote; nor to hold office

e. **Individual Member:**

1. Any individual enrolled in active work for the benefit of people living with rare diseases, or with a noted political or academic expertise on rare diseases and associated issues, as left to the appreciation of the Executive Board of the Committee.
 2. Eligible to attend and contribute to regular meetings; to sit on any ad hoc committees or working groups that may be set up in the course of the Committee's activities; but not to vote; nor to hold office
- f. All decisions pertaining to the membership of the Committee shall be reviewed, endorsed and enacted at the discretion of its Executive Board, the constitution of which is detailed further below.
- g. Dedicated sub-committees, task forces or working groups can be formed as and when necessary to fulfill an identified need for coordination on a specific issue, and to further the purposes of the Committee. The need for, and formation of, these dedicated bodies is to be decided as circumstances arise by the Executive Board.
- h. Membership of the Committee shall be effective only upon payment of required dues to the Treasurer, to the only exception of Individual Members who may be exonerated from



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membership dues in recognition of their voluntary work conducive to the purposes of the Committee.

4. Officers and Executive Board

- a. The responsibility of the Executive Board shall be to represent and support the Committee and exert supervision over its ongoing work. In turn, the Executive Board shall have the duty to keep the entire membership informed of its deliberations and decisions at regular meetings of the Committee.
- b. The Executive Board shall be composed of four (4) Officers – i.e. the Chairperson, the Vice-Chairperson, the Secretary, and the Treasurer – two (2) representatives of Associate Members, and two (2) Members-at-Large. No more than one (1) representative from any single organisation shall serve concurrently on the Executive Board.
- c. Individual Officers shall exert the following responsibilities and missions:
 1. The Chairperson shall preside over meetings, ensure that the activities of the Committee are executed effectively, serve as primary contact person in relations with CoNGO, and maintain all necessary communications with any other Substantive Committees of relevance as well as appropriate persons and departments in the United Nations system.
 2. The Chairperson, with the approval of the Executive Board, shall determine when the establishment of a Sub-Committee, Task Force or Working Group is necessary to fulfill a need and to further the purposes of the Committee. To this end, members of the Committee may submit to the Chairperson a detailed petition documenting their request and motives for establishing a new group within the Committee.
 3. The Vice Chairperson shall have leading responsibility for the programmatic planning of all plenary meetings, and also cover *ad interim* the responsibilities assigned hereabove to the Chairperson in case of absence or incapacity.
 4. The Secretary shall keep minutes of all plenary meetings, as well as a record of individual members' attendance, and arrange for the circulation of the said minutes to the entire membership. The Secretary shall also lead on the circulation of meeting announcements and all necessary background materials to the entire membership and to such other persons and organisations as the Executive Board may decide. The Secretary shall also supervise the preparation of an annual report of the Committee's activities, to be presented and adopted at annual plenary meetings of the Committee.
 5. The Treasurer shall collect membership dues and other contributions, and be responsible for the disbursement and maintenance of accounts. The Treasurer shall present at annual plenary meetings a brief report detailing the assets and liabilities of the Committee, to be filed with meeting minutes and communicated in parallel to CoNGO.
- d. If a vacancy occurs on the Executive Board, the position shall be filled by appointment of the Executive Board based on recommendations from the organisation whose



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representative has created the vacancy and from the Chairperson within thirty (30) days of the vacancy, and in line with the process laid out under section 5 below.

- e. Chairpersons of all Sub-Committees, Task Forces and Working Groups shall have direct responsibility to the Executive Board, and shall report to it at regular intervals. They may be invited to attend meetings of the Executive Board as and when deemed necessary.
- f. Should the need arise based on actual developments, the Chairperson and/or the Vice-Chairperson may at any moment in time convene a special meeting of the Executive Board to review the membership of a given organisation or individual on it, and propose any appropriate action. Should a motion of no confidence be proposed, it shall be deemed adopted if voted by an absolute majority of the Regular Members present on the Executive Board – i.e. a minimum of four (4) out of six (6) – and take effect immediately. The vacant position thus created may then be filled following the normal procedure detailed in section 5 below.

5. Nominations and Elections

- a. Regular and Associate Members of the Committee can nominate individuals from their organisations for a position on the Executive Board. Regular Members are entitled to propose names for the positions of Officers and Members-at-Large. Associate Members can propose names for the positions of representatives of Associate Members only.
- b. Unless special circumstances occur, left to the appreciation of the Executive Board, a candidate for the office of Chairperson should have served on the Executive Board for at least two (2) years. Similarly, a candidate for any other office should have been a member of the Committee for at least one (1) year. Officers shall be elected for a standard term of three (3) years, upon the conclusion of which they may be re-elected if nominated as per the following provisions.
- c. All nominations shall be communicated in writing to the Executive Board, at least one (1) month prior to the meeting at which the elections will take place.
- d. The election of the Executive Board shall take place at a plenary meeting of the Committee, and be decided by a vote of the majority of members present at the meeting. Election results shall be considered as taking full effect as of the first day of the following month.
- e. The Committee shall welcome and encourage the active involvement of persons living with rare diseases in its daily functioning, as well as their representation onto the Executive Board.

6. Meetings

- a. The Committee shall meet formally in plenary session at least once (1) a year.
- b. It shall be possible and, whenever necessary, encouraged for the Committee to organise ad hoc plenary meetings in between formal sessions to ensure continuity of work and regular updates to the Committee's members. Such ad hoc meetings may be conducted in various formats, e.g. informal meetings in other geographical locations, teleconferences or videoconferences, etc.



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- c. The Chairperson of the Executive Board, in consultation with other Officers, shall have primary responsibility for convening all plenary meetings of the Committee.
- d. Voting at plenary meetings shall be by a simple majority of those present as the normal rule, with each regular and associate member organisation having one (1) vote, and provided that a quorum of at least one third (1/3) of regular and associate member organisations are present on the day of a meeting.
- e. In the absence of a quorum, a postal or email ballot shall be taken.

7. Membership Dues

- a. The fiscal year of the Committee shall be defined as extending from January 1st through December 31st of a given year.
- b. The amounts of required membership dues shall be defined by vote of two-thirds of the Executive Board, with the possibility of defining different thresholds per category of membership.
- c. As per point 3.g., payment of membership dues shall constitute membership and entitle members to be involved from that point onwards in the regular work of the Committee.
- d. Annual dues shall be payable at the beginning of the fiscal year. A notice of delinquency shall be sent to members who have not paid their required dues by March 1st of a given year. Subsequent failure to pay by March 30th of that given year shall result in declaring the concerned member as not in good standing, and in the immediate cancellation of their membership rights and privileges, unless an exceptional derogation valid until the next plenary meeting is granted by the Executive Board based on appropriate considerations.

8. Committee Finances

- a. The Executive Board is hereby authorised to select and appoint the banks or depositories it deems proper for the funds of the Committee. The Executive Board shall have all competency to select and appoint the individuals who shall be authorised on behalf of the Committee to sign checks, order payments of money, or enter into contracts.
- b. The payment of membership dues to the Treasurer, as determined by the Executive Board, shall entitle members to fully participate in the activities of the Committee and receive the minutes of its meetings as well as other materials.

9. Representation

- a. Whenever the Committee is to be represented at a meeting of the CoNGO Board or any other meeting whatsoever, its formal representative and spokesperson shall be the Chairperson of the Executive Board, or an alternate appointed by the Chairperson.



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10. Permanent Secretariat

- a. To ensure adequate support to and continuity of the ongoing work of the Committee, as well as proper implementation of any decisions taken, the Committee and its Executive Board may decide to appoint a Permanent Secretariat of their choice.
- b. In any such case, it is agreed that the Committee and its Executive Board shall as first option designate one or both of the Committee's two initiating organizations, Ågrenska Foundation and EURORDIS, to lead a Permanent Secretariat of the Committee and to provide the required resources to sustain it, in collaboration with other Committee Members where appropriate.
- c. Only in the event that both Ågrenska Foundation and EURORDIS would be unable to provide the necessary staff resources, and that both organisations would explicitly and in writing waive the prerogative expressed in point 10.b, may the Committee and its Executive Board then be entitled to explore other options and partnerships for the establishment of a Permanent Secretariat.

11. Amendments to the Present By-Laws

- a. An amendment to the present By-Laws may only be proposed by a group of Regular or Associate members in good standing that together represent no less than one fourth (1/4) of the total number of Regular and Associate Members of the Committee.
- b. Upon fulfilment of the above condition, and to be considered for adoption, a proposed amendment shall first be submitted in writing to the Executive Board at least ninety (90) days prior to the plenary meeting at which it should be tabled and discussed.
- c. To ensure the Committee remains true to the spirit that presided over its creation, its two initiators, Ågrenska Foundation and EURORDIS, shall be consulted with immediate effect by the Executive Board upon receipt in writing of a proposed amendment. They may forward their opinion(s) within 20 days to the Executive Board for its consideration.
- d. Upon receipt of a proposed amendment, the Chairperson, in consultation with the Board, shall appoint an ad hoc By-Laws Sub-Committee and submit the proposal to it, together with any opinion(s) received from the initiating organisations. The By-Laws Sub Committee shall circulate the original proposed amendment as well as its own recommendation vis-à-vis it to all members at least thirty (30) days prior to the plenary meeting at which it should be tabled and discussed.
- e. Prior to, or during, the plenary meeting in question, all Regular and Associate Members may recommend further changes or additions to the original proposed amendment.
- f. A majority of two thirds (2/3) of voting members in good standing shall be required for the effective adoption of the proposed amendment.
- g. Upon its adoption, an amendment shall become part of the Committee's By-Laws and be effective from the closure of the meeting at which it was adopted.
- h. In the event of the dissolution of the Committee, the Executive Board, after the payment of all liabilities has been made, shall make assignments and disbursements of the remaining



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assets to CoNGO in a manner pursuant to, and compliant with, the purpose of the Committee as defined under section 2 above.

Revision History

- April 2016 Final adoption by CoNGO Board
- July 2016 Modification of paragraph 1.c. (date changed)