



RDI Advocacy Committee Terms of Reference

To fulfil Rare Diseases International (RDI)'s mission to be the voice of people living with rare diseases worldwide and in line with RDI's Joint Declaration "Rare Diseases an International Public Health Priority". It is deemed necessary to constitute an Advocacy Committee to speak with one voice to address the issue of rare diseases at a political and international level.

Purpose

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

Mandate, Composition & Selection

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.

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 and/or the Council appoints the members.

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.

Duration

The composition of Advocacy Committee is updated on an on-going basis. Appointments are for a defined period linked to the duration of their mandate in the RDI member organisation.

Organisation and Communication

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.

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.

The purpose of the Committee and a list of its members, will be listed on the RDI website.

Conflict of Interest

All candidates to Standing Committees and Working Groups shall disclose their potential competing interest.

Members of Standing Committees and Working Groups cannot receive payment for their duties.