orphanet

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Procedural document: International Advisory Board rules of procedure

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Instituts thématiques Inserm
Institut national de la santé et de la recherche médicale

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I. Introduction

1. Purpose/objectives

This procedure describes the membership of the Orphanet International Advisory Board, its mandate and its general rules of procedure.

2. Disclaimer

- This procedure is part of the RD-ACTION joint action 677024 which has received funding from the European Union's Health Programme (2014-2020).

- The content of this procedure represents the views of the author only and is his/her sole responsibility; it can not be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

3. Range of application

This procedure is intended for the International Advisory Board members and for the Orphanet audience.

4. References

- **Orphanet SOPs**
- International Advisory Board member list 2015-2018 in the additional information section of this document.

5. Definitions

International Advisory Board (IAB): is in charge of peer-reviewing the Orphanet project, it reports to the Orphanet Management Board (MB) and issues comments and recommendations which will enable the MB to define changes to be introduced to the project. This Board was established in the context of the evolution of Orphanet as an EU Joint Action in 2012, it is renewed now in the context of the joint action RD-ACTION 2015-2018.

Orphanet Management Board (MB): This Board is composed by Orphanet Country Coordinators and it is chaired by the scientific coordinator of the project at the Inserm.

Orphanet Coordinating Team: Orphanet is a consortium of 40 countries coordinated by the Inserm-based team in France

6. Filing and updates

This procedure is updated at least every three years by the Orphanet International Coordinator and as often as required. The most up-to-date version is available on the Orphanet website.

II. Membership

The members are nominated by the MB. They are nominated for 3 years and may be re-nominated.

The membership should cover the following fields: scientific databases; information technologies; ontology and nomenclature; communication and education; Research & Development; rare diseases, orphan drugs; and the patients' perspective.

III. Mandate

Board members are invited to provide comments on the Coordinating Team's annual activity report, on the annual satisfaction survey of the users, and to answer questions on particular issues at the request of the MB every year three months prior to the Orphanet Annual Meeting of the MB. The IAB members' input will be analysed and taken into consideration for strategic decisions to be taken at the Orphanet Annual Meeting.

The annual workload is estimated to be half a day per year.

IV. General Rules of Procedure

1. Three months prior to the Orphanet Annual Meeting, the Orphanet Coordinating Team sends by email all the material and questions on particular issues on behalf of the MB to the IAB members.

2. IAB members may request to have a conference call organised in order to discuss the material received with the Coordinating Team and/or other IAB members

3. IAB members provide comments/reccomendations/advices on the documents received and on the questions, in writing to the coordinating team

4. The Coordinating Team aggregates all comments, reccomendations, advices received by the IAB members in a report and sends it to the MB at least one month prior to the Orphanet Annual Meeting

5. The report is analysed by the MB members in order to consider IAB input on strategic decisions to be taken at the Orphanet Annual Meeting

V. Additional information

Compensation:
The members are not compensated for the time they dedicate to the project.

Sessions:
IAB members are not obliged to meet on a regular basis. They may select another way to coordinate their efforts (i.e. the Orphanet Coordinating Team may arrange a conference call upon request).

Members:

- Amos Bairoch, University of Geneva and Swiss Institute of Bioinformatics
- Adam Heathfield, PFIZER
- Pascal Garel, HOPE
- Martin Laimer, responsible for the care of patients (and families) with RD at Department of Dermatology of the PMU/SALK
- Gabor Pogany, HUFERDIS Hungarian Rare Diseases Patient Alliance and EURORDIS
- Peter N. Robinson, (HPO) Institute for Medical Genetics Universitätsklinikum Charité, Germany
- Bruno Sepodes, COMP chair, EMA

For any questions or comments, please contact us: contact.orphanet@inserm.fr

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http://www.orpha.net/orphacom/special/eproc_IAB_V02.pdf