



Discussion on EURORDIS Membership Criteria

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Membership Criteria

Membership criteria (adopted BoO September 2007 / updated November 2014 – in red)

- Rare disease organisation, according to EU prevalence criteria (5 / 10 000) – **as defined in EU Regulation on Orphan Medicinal Products(1999), Commission Communication on Rare Diseases(2008), Council Recommendation on an Action on Rare Diseases(2009), Directive on Patients' Right to Cross-Border HealthCare(2011)**
- Organisation from a European country – **48 countries as defined by EURORDIS based on definitions by EU, Council of Europe, WHO-Europe**
- The Governing Boards should be made up of a majority of rare disease patients or **family of patients**~~parents~~.
- Financial independence, particularly from the pharmaceutical industry (max. 50% of funding, from several companies)
- Non-profit status
- Proven **activities such as** patient support and/or advocacy activities and/or research~~activities~~

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- Patient organisation that have been recently (less than 1 year) created are invited to apply for “full membership”, but will qualify for a provisional status as “**associate member**” After one year or more, their membership status can be revised by the board of directors, upon examination of their first annual report or other documents provided to show activities-& proof of compliance with the membership rules-
- Annual Review process for regular re-assessment of FULL Members: Every year, a self reported update form and request for annual report & composition of the organisation’s Board of Directors is sent to
 1. Member organisations that present a candidate to the EURORDIS Board elections
 2. National Alliance & European Federations
 3. Full members which joined EURORDIS 10 years before the year of the update (in 2014, all full members which joined before December 2013 were sent the reassessment form.)

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One, or all, of these criteria could be waived in exceptional cases, due to the particularity of patient-driven organisations and of rare diseases, as well as for historical or contextual reasons. In all cases the Board of Directors makes the final decision regarding membership, and is not obliged to disclose the reasons of this internal decision, which are recorded in the minutes.

Rare disease organisations from countries outside of Europe, or exclusively dedicated to diseases with a higher prevalence than 5/10 000 can become **associate members**.

Questions/issues raised at General Assembly

- Funding difficulties faced by POs (especially European Federations):
 - Lack of sources of funding

and/or

 - Based in countries where in-kind contributions and volunteers cannot be monetised
- Receiving “waiver” of criteria + public information weakens position as Full member

Questions/issues raised at General Assembly

- Discussion & vote that took place during the AGA in Madrid was productive & indicated that our criteria are accepted by a broad percentage of our membership (91 Yes, 8 No, 7 Abstentions)
- There are actions however that can be taken to ease situation of European Federations:
 - Include information regarding in-kind contributions in financial information: this is a legitimate source of funding that can be taken into account by EURORDIS even if this is not included in formal accounting (*discussed in detail earlier today*)
 - Include in membership criteria that the specific funding criteria can be waived based on the Board's individual assessment of track record of activity and reputation; independence and structure of funding