



## Membership Criteria

---

The current EURORDIS membership criteria were adopted by the EURORDIS Board in 2007, and have been regularly revised since then with the most recent revision having taken place in November 2014.

The full membership criteria are as follows:

- 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
- 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

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.

## Reassessment process

---

In order to improve fairness and to enhance our membership base, EURORDIS introduced an annual review process for regular re-assessment of full Members, in 2012. The process was adopted by the EURORDIS Board of Directors and was included in our Work Plan 2013, which was adopted at the General Assembly in Dubrovnik in May 2013. It was decided that the re-assessment process would start with the following organisations:

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.*)