

Internal Rules

The Network and Council of European Rare Disease Federations (CEF)

As part of its mission to build a strong pan-European community of patient organisations and to develop a broader grassroots patient-centred community, EURORDIS has set the goal to better structure its group of European disease-specific networks. The European Network of Rare Disease European Federations is the way to reach that goal.

The Network of European Rare Disease Federations aims to complement the Council of National Alliances by increasing EURORDIS' outreach to local patient groups in new and future EU Member states as well as in all regions of Europe. While the Council of National Alliances represents the national level, the Network of European Rare Disease Federations represents the disease-specific level. Both the Council and the Network aim to enhance EURORDIS' outreach to local patient groups to build a pan-European community of people living with rare diseases. In addition, both are instrumental in i) building rare disease patient group capacities, ii) empowering patient advocates and ii) taking the patient voice to a higher and stronger level.

The European Network of Federations will specifically enhance EURORDIS' capacity to play an active role in priority policy areas such as European Reference Networks, European research projects, therapy development, web communities and information helplines.

Eligibility Criteria for European Federations

To join the Network of European Federations, the organisation must:

- Be a full or associate member of EURORDIS
- Federate national patient organisations for a specific rare disease/group of diseases from at least 3 European countries

General Objectives

The **Network** will enable **European Rare Disease Federations**:

- (a) to share information and experiences relevant to common activities and issues in their specific rare diseases at the European level,
- (b) to discuss and implement common activities within EURORDIS,
- (c) to foster or build their capacities as European Federations gathering patient groups from different countries for their specific disease or group of diseases,
- (d) to enhance their voice at the European level for their respective diseases,

(e) to –directly or indirectly- fight against the impact on the lives of people living with the rare diseases these European federations are specifically addressing.

(f) Collaborate with European Reference Networks (ERN) and participate European Patient Advocacy Groups (ePAGS)

Organisation:

The **Network of European Rare Diseases Federations** will gather European/international Rare Disease Federation members of EURORDIS. These Federations are legal entities, incorporated, with patient associations as members. They can be either full or associate members. There are no additional criteria proposed. To continue to be a member of the European Network, the European federations need to pay their annual EURORDIS membership fees, to participate regularly in the activities of the European Network and respect these Terms of Reference.

The Network will be coordinated by a Council of European Rare Disease Federations. The Council will be made up of representatives of European Federations of EURORDIS.

The **representative** is the contact person for EURORDIS, and must be committed to attending all Council Workshops (face to face or conference calls) and to reply to emails. Each European Federation can appoint a representative and an alternate. It is the responsibility of the representative to keep its alternate up-to-date on all Network activities.

Other RD Federations who are not yet legally incorporated, or which exist as informal networks can participate in the Council and Network as **Observers**.

The Council of European Rare Disease Federations will hold at least one **Annual Workshop of the European Network, including a one-day training**. Workshops will take place in different countries over time.

A dedicated **Web Section** is available on eurordis.org with all relevant information on the European Network, including the list of members. A CEF Facebook group is open to all CEF members.

General financial guidelines

EURORDIS will cover the cost of the yearly 2-day Workshop of the Council of European Networks of European RD Federations or of meetings of the Council in Brussels or Paris, including expenses such as: preparation, meeting room, equipment, coffee-break, lunch. EURORDIS will explore all possibilities to help cover expenses for federations which cannot afford participation, based on fellowships covering all or part of expenses.

Support to European Federations

Members of the Network of European Federations can apply for the yearly call "Support to European Federations", which aims at supporting the federations with their network meetings. (see Terms of References "Support to European Federations")

With the support of:

