EURORDIS
Rare Diseases Europe

Terms of Reference
The Network of European Rare Disease Federations

As part of its mission to build a strong pan-European community of patient organisations and to develop a broader grassroots patient-centred community, respectively, 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.
Currently, there are 25 European Federations who are members of EURORDIS, however there are more emerging, rare disease-specific European Federations, amongst which most are already in relation with or involved in EURORDIS' activities.
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.

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.

Specific Objectives:

1. To create and develop the Network of European Rare Disease Federations

The Network of European Rare Disease Federations will provide a platform for the exchange of experiences and information across existing European Federations working for different diseases or groups of diseases. The Network will be a link between EURORDIS and the members of the Federations. It will look for synergies and empower their members. The Network will generate more activity at the European level. EURORDIS will invite the European Federations who are not yet members of EURORDIS to apply for membership and to join the Network of European Rare Disease Federations.

2. To participate in the annual international Rare Disease Day

Each European Federation will be invited to participate in the implementation of Rare Disease Day and to customise the theme and focus to its specific disease.

All members of the Network of European Rare Disease Federations will be invited to join forces with EURORDIS in its activities in Brussels for Rare Disease Day.

3. To take part in the project Rare!Together

The project Rare!Together was launched in 2008 by EURORDIS to support the development of new Rare Disease federations, with the support of Medtronic Foundation and DG SanCo through the Operating Grant OPERA. The project will also develop a “Guide to Establishing and Developing a European Rare Disease Federation” and dedicated website section including a tool kit (developed with a wiki and a blog) useful to all networks and federations.

4. To promote and collaborate with European Reference Networks for Rare Diseases (ERN)

The Network of European Rare Disease Federations will provide a forum to actively collaborate with existing and future European Reference Networks for Rare Diseases by:

- Exchanging information and experiences of their collaborations with ERNs
- Initiating new applications for ERNs or partnership in application for ERNs
- Developing common tools to enhance the collaboration between ERNs and European RD Federations: annual meetings of the European patient group networks in conjunction with the ERN meetings; capacity building of patient advocates in patient databases and registries, in clinical trials and drug development & EU regulatory affairs, in research activities, in information activities; development of social guidelines; respite care services; therapeutic recreation programmes; etc
- Developing common tools for enhancing communication and the involvement and patients and families as active users of the ERNs and of the CoE: web online patient communities; European helpline; patients & parents leaflets; evaluation by patients; etc
- Using the Declaration(1) [1]to promote the need for ERNs for each of their diseases or group of diseases

5. To promote and collaborate with European research projects

The Network of European Rare Disease Federations will provide a forum to:

- Promote patient centred rare disease research priorities
- Disseminate information about rare disease research priorities and instruments
- Exchange information on developing and managing research project or about partnering in research projects
- Identify best practices and disseminate them to bridge the gap between research and patients and empower their capacities to be active players

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[1] Declaration on Common Principles : http://www.eurordis.org/article.php3?id_article=1296

6. To participate in other relevant EURORDIS activities

Other relevant activities may include:

- European Public Affairs activities
- EurordisCare surveys
- Eurordis surveys on Orphan Drug Availability

The Network of European Rare Disease Federations will inform EURORDIS about new actions to be developed and will promote the implementation of European decisions.
It will help EURORDIS to focus the efforts according to the real needs of patients with rare diseases.

Organisation:

The **Network of European Rare Diseases Federations** will gather European 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**. Workshops will take place in different countries over time.

Additional Council meetings may be organised in Brussels or Paris throughout the year.

A dedicated **Web Section** will be created on the EURORDIS Website with all relevant information on the European Network, a mailing list, a blog and wikis, as necessary.

A **leaflet** will be created to promote and raise the visibility of the European Network.

General financial guidelines

Eurordis will cover the cost of the yearly 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, equipments, coffee-break, lunch.

For the first meeting in May 2009, EURORDIS will also cover travel and accommodation expenses for one representative per European Federation invited to the Council Workshop. This is possible thanks to the funding from the DG SanCo Operating Grant. For the following years, travel and accommodation expenses will be covered by EURORDIS and will depend on financial capacities.

EURORDIS will not cover the travel and accommodation of representatives to additional Council meetings in Brussels or Paris, which will be at the expense of the European federations.

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