



EURORDIS' Council of European Rare Disease Federations

Programme of Support to European Rare Disease Federations Terms & Conditions 2012

EURORDIS is pleased to continue the programme "Support the European Rare Disease Federations" for the third year.

This programme was launched in the framework of the EURORDIS Council of European Federations under the responsibility of the EURORDIS' Board of Directors, chaired by Terkel Andersen, and of the Chief Executive Officer of EURORDIS who represents EURORDIS in the Operating Grant, Yann Le Cam. The manager responsible for developing, promoting and running the programme is Anja Helm.

The programme' resources for 2012 are 25 000 Euros. The programme is entirely funded by EURORDIS:

- Through the Operating Grant provided to EURORDIS by the European Commission and Executive Agency Health & Consumers
- By EURORDIS' own funds raised through the EURORDIS *Black Pearl* Gala Dinner.

Based, on evaluation as well as on available resources, it is EURORDIS intent to continue to expand this programme under the auspices of the Council of European Federations.

The aim of the programme is to promote patient empowerment through capacity building and European networking between patient organisation representatives in disease specific areas as well as to enhance the dialogue between these patient organisations' representatives and clinicians or academic European leaders in their area.

The programme is designed to provide seed money and add-on money to enhance the own efforts of the European Federations, and not to provide significant or recurrent financial support.

The purpose of the programme is to provide small, quick and flexible financial support for the organization or participation in European meetings, training sessions, project development, workshops and conferences.

With the support of:





All European Rare Disease Federations that are members of EURORDIS can apply for this support.

European Networks that are not yet incorporated can apply for this support if one of their member organisations is a full member of EURORDIS and handles the financial aspects.

European Federations wishing to apply to this programme should fill out the attached application form and send it to: anja.helm@eurordis.org

Scale of support	Max. support in €
European Federation or Network Board of Directors meeting	600
European Project Development Meeting	1000
European Networking Meeting	1200
European Training	2000
European Disease Specific Conference seed money	3000
Individual travel allowance <i>preference is given to patient representatives from Eastern Europe or disabled people requiring personal assistant</i>	400/pers.

Support is limited to a total of 3000 € / year per European Federation.

The application will be examined by the Steering Committee of the Programme of Support to European Rare Disease Federation. The Committee is made up of one former board member of EURORDIS, two current board members and one staff member. In 2012, the Committee is composed of Lesley Greene (UK, former EURORDIS President), Dorica Dan (Romania, Officer EURORDIS), Dimitrios Synodinos, (Greece, Treasurer of EURORDIS) and Anja Helm (Senior Manager of Relations with Patient Organisations).

A written reply will be sent in the 30 days following the reception of the application form duly completed.

Financial support will be paid to successful applicants once the “Reimbursement Claim Form” has been returned to EURORDIS, accompanied by the relevant invoices, receipts, tickets and boarding passes. All claims will be treated within a one month period after reception.

With the support of:





Applicants are required to follow the EURORDIS reimbursement procedure (Annexe 1). Please join all receipts to one “Reimbursement Claim Form” to facilitate our administrative treatment of the documents. To claim for example 600 €, you must be able to justify at least 600 € in receipts.

Please remember that this project has limited resources. We rely on European federation’s sense of solidarity and fairness to limit their request to what they actually need and well targeted purpose to allow support to a significant number of European Federations. Financial support will be given along the lines of the programme purpose on a “first come first served” basis with a **priority to those federations most in need of financial aid, notably the smaller and most recent federations.**

EURORDIS is aware that the meetings, workshops, conferences and trainings organised by European Rare Diseases Federations are co-sponsored by pharmaceutical and biotech industry. Therefore, all beneficiaries are invited

- (a) to read and adopt the EURORDIS’ Policy on Relationships with Commercial Companies and/or (annexe 2)
- (b) to read and sign the “Code of practice between Patient Organisations and the Health Care Industry”.(annexe 3)

In addition or in place of applying to this programme, European Federations can ask for two other forms of support from EURORDIS for the same purpose:

- The EURORDIS’ Patronage of their event; please refer to document: ”Eurordis Patronage”(annexe 4)
- In-Kind support in the offices of EURORDIS in Paris (Rare Disease Platform, Paris XIV, where we have meeting rooms of several size up to 100 seats which can be booked in advance and provided for free, and we can also provide name of hotels close by, catering service and restaurant, all with reasonable prices) and in Brussels (Rue de la Loi, in the European District, where we have a meeting room which can accommodate up to 12 persons).

It is important to note that this programme of support to European Rare Disease Federations is not conceived as a standalone programme, but is part of a more global EURORDIS programme of actions intended to empower European networking of rare disease patient organisations, namely but not limited to:

With the support of:





- The Council of European Rare Disease Federations, created in 2009, providing a network and visibility,
 - The Workshops of the Council, at least once a year (Capacity building sessions & training for the members of the Council),
 - The Rare!Together Project which provides monitoring of new and emerging European Rare Disease Federations as well as a 'work in progress' Guide on Best Practices on creating, developing and managing a European Rare Disease Federation or Network
 - Patient Fellowships Programme to take part in the European Conference on Rare Diseases (ECRD), the DIA EuroMeeting and fee waivers to all DIA meetings in Europe
 - The On Line Patient Community tool to create web social media for their European network or federations
 - The Summer School Sessions on Drug development, Clinical Trials and EU Regulatory Affairs
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