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## EURORDIS' Council of European Rare Disease Federations

### Programme of Support to European Rare Disease Federations Terms & Conditions 2020

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EURORDIS is pleased to continue the programme “Support the European Rare Disease Federations” for the 11<sup>th</sup> 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 is co-funded by the European Commission / Executive Agency Health & Consumers in the framework of the EURORDIS Operating Grant and by EURORDIS own resources. 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.**

Meetings supported in the framework of this programme must take place in **Europe**.

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.

All European Rare Disease Federations that are full 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 form and send it to: [anja.helm@eurordis.org](mailto:anja.helm@eurordis.org) before March 6<sup>th</sup> 2020.

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	1800
European Disease Specific Conference seed money	2200
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 2200 € / 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 current board members and one staff member. In 2020 the Committee is composed Dorica Dan (Romania), Dimitrios Synodinos, (Greece, Treasurer of EURORDIS) Geske Wehr (Germany, General Secretary) and Anja Helm (Senior Manager of Relations with Patient Organisations).

A written reply will be sent end of March 2020.

Financial support will be paid to successful applicants once the short report and “Reimbursement Claim Form” has been returned to EURORDIS, accompanied by the relevant **invoices and receipts**. All claims must be sent in within **30 days** after the supported meeting took place and will be treated within a one-month period after reception.

Applicants are required to follow the EURORDIS reimbursement procedure. 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.

**All selected applicants are required to send us an outcome report after their meeting, with the reimbursement claim**

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 and those that have not yet benefitted from the support programme.**

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 **required**

- (a) To send us their latest financial report
- (b) To read and adopt the EURORDIS' [Policy on Relationships with Commercial Companies](#) and/or
- (c) to read and sign the "[Code of practice between Patient Organisations and the Health Care Industry](#)"

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 (upon request to [anja.helm@eurordis.org](mailto:anja.helm@eurordis.org))
- In-Kind support in the offices of EURORDIS in Paris where we can provide free meeting rooms of several sizes

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:

- The Council of European Rare Disease Federations ([CEF](#)), created in 2009, providing a network and visibility,
- The [CEF facebook](#) page
- The Workshops of the Council, that take place at least once a year (Capacity building sessions & training for the members of the Council),
- The [Rare!Together](#) guide on creating, a European Rare Disease Federation or Network
- Patient Fellowships Programme to take part in the EURORDIS Membership Meeting, European Conference on Rare Diseases (ECRD), Multi-stakeholders Symposium in Brussels
- The On Line Patient Community tool [RareConnect](#)
- The [Open Academy](#), including **Summer School** (Drug development, Clinical Trials and EU Regulatory Affairs), **Winter School** (Scientific Innovation and Translational Research) and **Digital Academy**.