

2nd Workshop of the Council of European Rare Disease Federations

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EURORDIS Support to European Rare Disease Federations and

- European Rare Disease
Networks

Exchange of Information, Experience and other Networking Activities

- Creation of a Network of Rare Disease Federations coordinated by a Council of European Rare Disease Federations as detailed in the Terms of Reference
- Support for participation in annual workshops addressing common needs of European Rare Disease Federations and Networks
- Participation in Rare!Together, a project dedicated to the development of new Rare Disease federations, creation of a “how to” tool kit via a the dedicated wiki tool (raretogether.eurordis.org), and publication of a “Guide to Establishing and Developing a European Rare Disease Federation”
- Reporting on achievements of European Rare Disease Federations and Networks in EURORDIS newsletter

Access to Capacity Building and Empowerment

- Possible participation in Eurordis Summer School on clinical trials, drug development and EU regulatory affairs (next session 2011)
- Possible participation in EURORDIS task forces (Paediatric Drugs, Orphan Drugs, Drug Information and Transparency Access)
- Sharing of monthly reports of EURORDIS representatives at the EMEA
- Support to involvement in the EMEA regulatory process (e.g. protocol assistance workshops, external experts in committee's procedures)
- Help EFs to become an eligible organisation with the EMEA

Enabling Involvement in Addressing Common Issues in EU Policy (step by step)

- Link with EURORDIS representatives in the EU Committee of Experts on Rare Diseases
- Involvement in the working groups of the EU Committee of Experts on Rare Diseases
- Dissemination of information on relevant EU policies or legislations
- Consultation and involvement in common policy positions
- EURORDIS can be consulted on disease specific issues
- Policy positions can be submitted to the Council of Federations for peer review

Community Building of European Rare Disease Federations

- Facilitation of Meetings of European Rare Disease Federation or Network meetings, in particular back to back with ECRD and Annual Membership Meetings
- Creation of Online Patient Communities: providing the tool, adapting it to specific disease community needs and providing the methodology to allow fruitful networking amongst members

Raising Awareness

- Sharing all tools created for annual Rare Disease Day Campaign and enhance opportunities for visibility and access to key people around the annual RDDay event in Brussels (to be defined)
- Events organised across Europe can be announced on the “Europe” page of www.rarediseasday.org
- European Federations can invite up to 2 participants to the European workshop on 1st of March 2010
- Access to Play Decide Games and trainings
- Dedicated section on the EURORDIS website and the Rare Together wiki

Potential Financial Instruments for European Rare Disease Federations and European Rare Disease Networks

Brussels

Financial support for European Federations

Hypothesis 1:

Direct support from EURORDIS to EF

Hypothesis 2:

Mini Operating Grants (Direct DG SANCO to EF)

Hypothesis 3

Facilitate access to EC support

Hypothesis 1: Direct support from EURORDIS to EF

EURORDIS cannot give a lump sum directly to a Federation
BUT indirect support, by reimbursing, for example travel and hotel expenses for:

- Board Meetings of the EF
- Meetings to develop a project (ERN)
- Meetings in new & future Member states

Hypothesis 1: Direct support from EURORDIS to EF

Drawbacks:

- Financial element in the relation between Eurordis and Efs
⇒ Potential problems ?
- Criteria have to be defined on how to select the beneficiaries
⇒ Who decides?
- Not enough money for every federation member of EURORDIS
⇒ Competition ?
- EURORDIS has to find 40% co-funding for every grant received from the EC
⇒ Financial risk

Hypothesis 2: Mini Operating Grants (DG SANCO) Direct DG SANCO to EF

To be discussed (and developed) directly with the European Commission/DG SANCO

Drawback:

the DG SANCO has limited resources (in terms of time and money) and does not wish to break down resources into many separate grants

Hypothesis 3

Facilitate access to EC support

Eurordis could help European Federations to understand and navigate the different financial support programmes of the European Commission:

- Conference grants (EAHC)
- Information Networks (EAHC)
- Research Grants (DG Research)
- Standard Work Package in European Reference Networks (DG SANCO, EAHC)

How?

Through a Capacity Building/Training workshop

Capacity building Workshop *to be discussed*

- ❖ *When?: June/July 2010*
- ❖ *Location to be defined (at the occasion of another meeting?)*
- ❖ *Themes:*
 - *Applying for funding from the European Commission*
 - *Applying for grants from commercial companies and private foundations*
 - *Developing partnerships with European Networks of Centres of Expertise (or with sponsors of clinical trials)*