

**1st Workshop of the
Council of European Rare Disease Federations
Athens, 7 May 2009**

Participants:

DEBRA Europe : John Dart

EU MGA : Peter Finney, Josipa Gazibar, Dubravka Jurenic

European Chromosome 11 Network: Arne Eiwien

European Network of Ichtyosis: Geske Wehr

Federation of European Williams Syndrome, Gabor Pogany

HSP Europe: Fina Mateo, Fernando Gonzaleez

IPOPI: José Drabwell

Myeloma Euronet: Viorica Cursaru

PHA Europe: Marzia Predieri

OIFE: Ute Wallentin

Thalassaemia International Federation: Kaisa Immonen-Charalambours, Androulla Eleftheriou

EURORDIS: Yann le Cam, Anna Kole, Anja Helm, Denis Costello, François Houyez, Rob Camp

The first meeting of the Council of European Rare Disease Federations gathered existing and fledgling European Federations for Rare Diseases interested in the creation of a European network to empower each other and act together as a group of patient organisations having interests in common.

The following items, as outlined in the General Terms of Reference of the network, were discussed:

The Network of European Rare Disease Federations

Discussion facilitated by Yann le Cam, CEO

Based on the General Terms of Reference, all participants agree that the general objectives they expect of this network are to:

- Provide a platform for information & best practice sharing in developing their respective European Federations

The Network is primarily intended to this aim and the means to achieve this aim are: the Council, its face to face workshops, its webinars, its online community and the project Rare!Together.

In addition, the participants are willing to share the documents they have created for their networks, for example on “How to create a patient organization” IPOPI, or “How to begin a European Federation (PHA). This could be shared through the online community.

- Political involvement of patient organizations at the European level.

The participants expressed particular interest in the following key issues which they expect, should be addressed by the Network: Centres of Expertise & European Reference Networks

(Promote the creation of European Reference Networks, Promote good practices of relationship between European Federations and ERNs, long term sustainability in the EU Public Health Strategy 2014-2020); Mobility of patients & reimbursement of provision of care in another EU Member State (aiming at easy & fair access to treatment with no upfront payment by families); Availability of Orphan Drugs & other Rare Disease Therapies

Actions:

- All participants strongly welcomed the EURORDIS' initiative to create this European Network and Council
- All participants adhere to the General Terms of Reference as adopted by the EURORDIS' Board of Directors and agree they are appropriate
- Participants now expect an action plan (which we will call "Specific Terms of Reference" of the Council of European Rare Disease Federations) in order to focus on more specific objectives with deadlines and assignments so to measure progress and be able to communicate them back to their respective Board and members.
- Assignment: A drafting group of the Specific Terms of Reference has been formed which includes:
 - o EURORDIS: Yann le Cam, Anja Helm , Anna Kole, François Houyez, Rob Camp
 - o José Drabwell (IPOPI)
 - o John Dart (Debra Europe)
 - o Peter Finney (EU MGA).
- Process and timeline:
 1. Yann will send a first draft of the Specific Terms of Reference during the Summer 2009 based on:
 - o EURORDIS' Strategy 2010-2015
 - o The General Terms of Reference +
 - o discussion during 1st CEF Workshop 7 May in Athens
 2. The group will collaborate via e-mailing and one conference call with the aim of having Specific Terms of Reference ready before the next face-to-face meeting in Fall 2009.
 - 3. The outline of the Specific Terms of Reference are:
 - (a) Exchange of information and experience on establishing and developing a European Rare Disease Federation (through CEF, its Workshops, a leaflet, the Webinars, the Council of Federations Online Community, the project Rare!Together)
 - (b) Access to care (the European Reference Networks, patient mobility and reimbursement on cross border health care, drug availability)
 - (c) Awareness (the Rare Disease Day with a common event in Brussels) & Policy (Consultation on some Position Papers and Contributions)
 - 4. In the first year (2009), the Council of European Rare Disease Federations will meet twice. The second meeting will take place probably in Brussels at the end of the year. Before this meeting, a conference call or webinar will be organized to follow up on actions.

Website: Presentation of the new section and online community dedicated to European RD Federations

Discussion facilitated by Denis Costello, Web Communications Manager

Denis presents:

- The future section on European Federations in EURORDIS Website

- The future Online Communities, one of which could be dedicated to European Rare Disease Federations. On this community, federations will be able to exchange information and post supportive documents (online library) for example on how EU policy works, case studies, mentoring topics etc.

Actions:

- An Online Communities of Patient Advocates involved in European Rare Disease Federations will be launch by Denis in November as one of the first pilots of On Line Communities of Patient Advocates
- Assignments::Ute Wallentin (OIFE, Germany) and Viorica Cursaru (Myeloma Euronet, Romania) volunteered to be moderators of this community

The Polka Project: Presentation of the Patient preferred policy scenario and how to take part in it

Discussion facilitated by Francois Houyez, POLKA Project Manager & Health Policy Officer (presentation attached)

François presented the POLKA project and Play Decide Sessions. European Federations are invited to play a crucial role in the implementing of these sessions.

Actions:

- Anna will keep European Federations informed as Play Decide Games are developed

Rare! Together Project

Discussion facilitated by Rob Camp, Patient Advocacy Consultant

With the Rare!Together project, EURORDIS plans over a 3 year period:

1. To help in the creation, operation and management of 2 to 3 European Federations, via this mentoring project
2. To develop a “*Guide to Establishing and Developing a European Rare Disease Federation*”,

The guide is currently being developed on a wiki:

http://raretogether.eurordis.org/index.php/Main_Page

The ultimate objective of Rare!Together will be the empowerment of targeted patient groupsthrough information, training, close mentoring, networking, and exchange of experience and good practices.

Actions:

- The existing federations are invited to participate notably in the wiki project, sharing their experience in the creation of a European federation.
- Participants propose to add the following topics to the wiki:
 - o Code of conduct with the pharmaceutical industry
 - o Glossary of most used terms
 - o Fundraising: examples of successful campaigns.
- The Rare!Together Wiki will be included as one feature of the On Line Community

Rare Disease Day

Discussion facilitated by Paloma Tejada, Communication Manager

Presentation attached

Paloma Tejada informed participants of the Rare Disease Day concept, implementation & outcomes 2008 as well as 2009 and plans for 2010.

The focus proposed for RDD 2010 is: Bridging patients and scientists on research or addressing the genetic ethical issues.

Play Decide sessions will be organised all over Europe on topics related to genetics:

- neonatal screening
- pre-implantation genetic diagnosis
- genetic testing and counseling

Actions:

- Most participants are willing that their respective European Federations take an active part in next Rare Disease Day
- All participants welcome the idea of joining in a common event organised by EURORDIS in Brussels around 28 February 2010 for which the objective, nature and scope are still to be defined
- Viorica Cursaru and José Drabwell volunteered to participate in the group that will develop the topic, knowing that the genetic issue can be tricky. Representatives of the Council of National Alliance are the major part of this drafting group that will exchange via e-mail with Paloma. The decision on focus will be based on this consultation with national alliances and final decision will be made by the Board of Directors in early July.

European Reference Networks of Centres of Expertise

Discussion facilitated by Anna Kole, Public Health Coordinator

Presentation attached

Federations are obviously interested in the establishment of European Reference Networks of Centres of Expertise as well as European Research Networks on their diseases.

The discussion covered the objectives of: promoting such networks, promoting good practice of collaboration between these networks of experts and the European Federations of patient groups, promoting financial support from the Commission toward European Federations.

Participants asked if EURORDIS could gather all willing European Federations into one project so to ask for funding to the DG SanCo. Yann declined this possibility as EURORDIS will not take the legal and financial responsibility for the use of public funds by these European Federations, neither would commit to such a huge administrative project management. Also it would be good in the short term, but disempowering in the long term for European Federations themselves.

Yann proposed the following alternative idea: EURORDIS could develop, with the Council of Federations, a 'Standard Work Package' to be included in EC funded projects with several options for "European Federations". The template for a Standard Work Package could be promoted to DG SanCo and submitted for endorsement by the Committee of Experts on Rare Diseases with the aim that it would be compulsory for each new or renewed European

Reference Network to have this Work Package as part of their project proposal. This Work Package would aim at supporting operations of European Federations while bridging the dialogue between patient representatives and experts; it would specifically include funding for:

- One yearly meeting of patient groups along side the European Reference Network Meetings
- A minimum secretariat based on certain criteria
- A website and an Online community for the specific disease operated through the EURORDIS Web Platform
- Production of public and patient information
- Training sessions for patient representatives on clinical trials, EU regulatory affairs, patient databases and registries

Ultimately, collaboration between researchers and patient organisations would be encouraged and European Federations would be reinforced both financially and politically.