**4th Council of European RD Federations**
**Paris, 30/6 + 1/7/2011**
**Meeting Report**

Representatives of 16 European Rare Disease Federations and networks met in Paris to discuss common issues, exchange information and attend a one day workshop on clinical trials.

**Rare Disease Day ,** Paloma Tejada, EURORDIS
*(presentation on http://www.eurordis.org/content/council-european-rare-disease-federations)*

European Federations (EF) are strongly encouraged to participate in the annual Rare Disease Day. (www.rarediseaseday.org)

2012 is a leap year so RDDay will fall once again on a rare day, the 29th of February. It will be the 5th RDDay and should be a very special event.

It has been decided to start the groundwork necessary to get RDDay recognised as an official day in the UN Calendar. The EC and the EUCERD will start working to present a Resolution on RD to the General Assembly of the WHO in 2013- 2014.

At the advocacy level, the goal in Europe is to get RD higher in the public health and research agendas, and to get more budget for RDs. This is especially timely since the 3rd EU Public Health Programme and 8th Research Framework Programme are been negotiated now for the period 2014-2020.
The theme in 2012 is **Solidarity**

- Between patients
- Between carers
- Between rare diseases
- Between rare and common diseases
- Between countries
- Between society and rare disease patients
- Between society as a whole and vulnerable groups

The theme is very wide and general. RDD participants could use it to bring forward issues that are important for the rare disease patient community, e.g. reimbursement, access to orphan drugs, healthcare pathways, multidisciplinary care, international research infrastructures, cross border healthcare, pooling of expertise, European reference networks, etc.

How can European Federations get involved?

Most participants agreed they would encourage their members to participate at the national level but some have trouble identifying concrete ways of participating at the European or international level.

The following suggestions to get involved were mentioned:

- Attend the European advocacy event organised by EURORDIS in Brussels
- Invite MEPs that have shown interest for the disease and promote the event amongst their contacts, relay information about the livestream broadcast in order to get more people tune in
- Organise an event for Rare Disease Day and advertise it in the 'Europe' page of the Country by Country section of www.rarediseaseday.org
- Target a different audience than the National Alliances (mostly focused on National Plans). EF could organise events in a Centre of Expertise or with a Learned medical society or with an international network of researchers. For example, DEBRA is formalising its network of expertise and should probably launch in on RDD.
- Use the results of the Eurobarometer survey on rare diseases (http://www.eurordis.org/content/eurobarometer-rare-disease-awareness ) to raise awareness about their disease (CF Europe used the relevant results in their Annual Meeting)
- Organise an awareness-raising campaign for your own disease and latch on to the general RDD campaign, like the Spina Bifida International Federation or the PHA Europe who used the RDD logo and launched their campaigns that day (see more details below)
- Communicate about RDD on their existing disease-specific 'days'.

Tasks:

1. Collect information on disease-specific days and post them on the RDD and EURORDIS websites
2. Share good examples of awareness raising campaigns (i.e. PHA and CF week) and post them on EURORDIS website and on Rare!Together
3. Use RDD framework to incorporate other disease-specific campaigns
4. Improve the promotion of the Brussels event, including the broadcast livestream

*EURORDIS invites all CEF members to send this information to anja.helm@eurordis.org.*

**Case study PHA "breathtaking" RDD campaign,** Pisana Ferrari, PHA Europe
*(presentation on http://www.eurordis.org/content/council-european-rare-disease-federations)*

The main objective of the PHA campaign was to raise awareness.

Pulmonary Hypertension is a rare and incurable lung/heart condition which leads to heart failure or lung transplant. PH is still relatively unknown; late diagnosis and treatment have dramatic effects on prognosis. The differences in access to approved drugs, surgery and transplantation are big across Europe

PHA Europe is a federation created in 2003 that now has 20 member organisations in Europe.

7 member organisations joined the campaign and received flyers, posters and leaflets. Launch events took place in Brussels and Vienna attended by PHAE President and VP. National events took place in Bulgaria, Germany, Hungary, Norway, Poland, Portugal, Spain as well as Czech Republic, Italy and Slovakia

Follow up with Facebook application, videos on Youtube, other events

The national organisations were in charge of printing &distributing material, rental of spaces, organisation of events, media coverage and follow up.

The campaign results are very good, with extensive dissemination of information, great media coverage, increased visibility for PH and the federation and community building.

Pisana underlined the importance of having a dedicated staff or volunteer to coordinate the campaign full time, with the help of a communication agency. Funding is of course crucial, in the case of PH all the funding came from one pharmaceutical company. PHA Europe had the support of their scientific committee, who checked the medical information that was distributed and participated in some events.

Lessons learned:

Such an event could be organised cheaper using in house resources and pro bono work

**Cross Border Health Care,** Yann le Cam

This directive has been officially adopted by the Council of Ministers of the EU in April 2011.

Member states will have 30 months to implement it and adapt it to their national legislation.

An important step forward for rare disease patients is that Rare Diseases are now mentioned in a European legislative text (a directive is a binding legal instrument, unlike a Commission Communication or Council Recommendation)

Moreover the Directive promotes European Reference Networks in particular for rare diseases. European Reference Networks are networks of centres of expertise, of diagnostic laboratories or of experts.

New in this directive is a special provision for RD patients to ease diagnosis in other countries .The directive clarifies the rules of who pays for what across countries, yet one has to keep in mind that this directive was made first and foremost for national social securities. Another progress contained in the Directive is the clarification of rules and procedures to obtain reimbursement.

Information centres are to be set up in all Member States countries offering patients data on treatments, providers and levels of reimbursement across the EU.

The national transposition of the directive will be difficult, every country will do something different. The EUCERD's work plan includes the developing of guidance on how to transpose the directive nationally. More information on http://www.eucerd.eu
To implement the directive, a working group "Mobility of patients" has been set up, which doesn't include any patient representatives, researchers or health care professionals, but people from social security services.

*European federations are asked to monitor the work of European Referenec Networks and follow-up on patient mobility by flagging examples where patients are not being reimbursed in another country as stipulated in the CBHC Directive.*

**A new European tool**: www.clinicaltrialsregister.eu, *Francois Houyez*

The EU Clinical Trials Register website allows you to search for information on clinical trials in European Union (EU) member states and the European Economic Area (EEA) and clinical trials which are conducted outside the EU/EEA if they form part of a pediatric investigation plan (PIP). It is is hosted by the European Medicines Agency (EMA). Users can find information on the design of each clinical trial, the sponsor, the investigational medicinal products and therapeutic areas involved and the status of the clinical trial.
This database on European clinical trials has recently been opened to the general public.

For more information: http://www.ema.europa.eu/

**Rare Disease Communities – www.rarediseasecommunities.org,** *Denis Costello*

The Rare Disease Communities project is part of the strategic partnership signed in 2009 between Eurordis, the European Rare Disease Organization and NORD, the National Organization for Rare Disorders. The communities are guaranteed by Eurordis and NORD with a view towards fostering international collaboration amongst patient groups and protecting the voice of patients from purely commercial interests.

The main idea behind the project is to create an online social network for patients and caregivers living with rare diseases in order to enable the sharing of experiences and increase access to quality information. International patient organizations collaborate to develop these communities along with Eurordis and NORD. Patient organizations play a key role in governing and communicating to the community, recruiting forum moderators, and being sources of information to patients and their families.

The website is split into three sections: *What*, *Meet*, and *Learn*. The *What* section features patient stories and blog style updates from patients and patient organization representatives. The *Meet*

section is a forum, moderated by volunteers and offering human translation services across 5 languages: English, French, Spanish, Italian, and German. Since patients and families are spread thinly across the globe, it is vital to create a space where information can be shared with the best possible translation. Finally, the Learn section is a resource of information in the form of frequently asked questions, documents, recently publish news and scientific articles, upcoming events, and patient organization's contact information.
Users interested in discussing these diseases register on the website. After registering, a user can upload their story on living with the disease through a link in their profile page. The story then automatically is added to the What section and is translated into all of the platform's languages. Users can also participate in Forum discussions or post their own questions. If a user sees a message on the Forum that is not in their language (French, German, Italian, Spanish, or English), they request a translation be made. Within a few hours, the message is translated and uploaded automatically to the website. The user that requested the translation is also sent an email with the translated content.

The project is financed by European Commission, the French Telethon (AFM) and the French Federation of Pharmaceuticals (LEEM) and a diverse array of corporate partners who play no role in the operation of these communities.

Any questions on the Rare Disease Communities project can be addressed to Rob Pleticha, the Online Patient Communities Coordinator at Eurordis at: robert.pleticha@eurordis.org

**Rare Together update**

As some new and emerging networks have joined the CE, a short question & answer session took place on issues relating to the creation of a European Rare Disease Federation.
Old & new Topics that were discussed and can be found on the Rare Together website:

- Membership and voting rights
- Membership fees
- Tax relief on donations in another Member State
- Avocacy tools – Eurobarometer survey

**Next meeting of the CEF**
Participants agreed to keep p the 2 day format (one day CEF meeting, one day training) and to hold the meeting in the month of June.
Proposed topics for next year's training:

- -Registries
- -Research coordination & promotion
- -Promotion of translational research

The topic will be chosen closer to date by the whole CEF group.