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## **EUCERD Joint Action WP4 & WP8**

### **Workshop on Rare Disease European Reference Networks and Structural Funds**

28-29<sup>th</sup> October 2014

Casa dell'Aviatore, Viale dell'Università, 20 - Rome (Italy)

**Aim of the Workshop:** To provide a forum for Member State (MS) Representatives (both Commission Expert Group members and Competent National Authorities) to discuss the implementation of rare disease (RD) ERNs and how the Expert Group can provide ongoing input and support during this phase and beyond. Key legislative and policy documents acknowledge RD as a focal area for ERNs, given the specificities, challenges, and the potential for high added-value through a collaborative European approach, specifically: the Council Recommendation 2009/C151/02 on an Action in the Field of Rare Diseases; Commission Communication - Rare Diseases, Europe's Challenge; Cross-Border Healthcare Directive (2011/24/EU) Articles 12 and 13; EUCERD Recommendations on RD ERNs and the Commission Delegated Acts (2014/286/EU). In the implementation of the Delegated Acts there has been a convergence on common transversal criteria and conditions for the assessment and establishment of ERNs.

**The workshop will focus on the ways in which MS might address the specificities of RD in line with the requirements of this European legislation, in preparation for the first calls for ERNs to be announced in 2015. It will facilitate discussions on how to collaborate, organise and mobilise national resources and the RD community to ensure RD ERNs will address the needs of all RD patients across Europe.**

An additional, related aim is to explore the potential of structural funds to support RD infrastructure, including RD ERNs themselves.

#### **Specific questions to be addressed include:**

1. What is the most suitable 'model' for RD ERNs? Sharing expertise and identifying the pertinent issues for MS endorsement of centres participating in RD ERNs, and how MS use this framework
2. How can RD be strategically grouped to ultimately enable RD ERNs to benefit MS healthcare systems by alleviating challenges such as scarcity of resources and meet the needs of all RD patients?
3. How might structural funds support RD ERNs (and additional activities delineated within the National Plans and Strategies for RD?)
4. What recommendations can be made from the Expert Group based on the existing EUCERD recommendations but in the context of the Delegated Acts?

## Day 1: Tuesday 28<sup>th</sup> October 2014

09:00-09:10 Welcome to the Workshop. Where do we want the workshop to go? What are the expectations of the participants? (*Kate Bushby and Domenica Taruscio*)

### **SESSION 1- RD ERNs: Context and national experiences** (relates to workshop Question 1)

09:10-09:40 The ERN Policy framework (*Kate Bushby and Enrique Terol*)

09:40-10:00 How are the EU MS preparing for RD ERNs? (*Enrique Terol and Domenica Taruscio*)

10:00-10:30 WP7 conclusions to date: Networking of CEs and current readiness of the field for ERNs (*Francesc Palau and Richard Woolley*)

#### **10:30-10:50 Coffee Break**

10:50-11:10 Implementation of European Reference Networks: Timeline and Calls (*Enrique Terol*)

**11:10-13:00 Round Table - How are MS approaching the issue of ERNs for RD?** To be followed by **Discussion and Q & A on Session 1** (*Moderators Kate Bushby and Francesc Palau*)

**Output of Session 1:** *A discussion document/non-paper on national experiences and designation of centres to participate in ERNs, to serve as information to the Commission Expert Group on RD.*

#### **13:00-14:00 Lunch**

### **SESSION 2: Models and Organisation of RD ERNs** (relates to workshop Question2)

14:00-14:30 Presentation of Preparatory Discussion Document (*Kate Bushby*)

14:30-15:00 Patient's perspective on added value of strategically-conceived Rare Disease ERNs (*Yann Le Cam*)

15:00-15:20 State of the art of rare diseases networks in EU (*Domenica Taruscio*)

15:20-15:40 Disease grouping and models for RD ERNs (*Teresinha Evangelista and Victoria Hedley*)

#### **15:40-16:00 Coffee Break**

**16:00-18:00 Discussion on Session 2 to include Q&A session** (*Moderators Yann le Cam and Enrique Terol*)

**Output of Session 2:** *Guidance for dissemination to Expert Group on Rare Diseases.*

#### **18:00 Day 1 Ends**

## Day 2: Wednesday 29<sup>th</sup> October 2014

### **SESSION 3: Opportunities to support RD ERNs and RD activities using European Structural Investment Funds** (relates to workshop Question 3)

09:00-09:10 Introduction to Session 3 (*Kate Bushby, Domenica Taruscio and Yann Le Cam*)

09:10-09:30 European Structural and Investment Funds (ESIF) 2014-2020 (*Gerhard Steffes*)

09:30-10:00 Supporting EU MS for the effective use of ESIF for health investments in the programming period 2014 - 2020 (*Romana Smetankova*)

#### **10:20-10:50 Coffee Break**

10:50-11:10 Accessing and using Structural Funds - Greek experience with mental health reform and its implications for tackling rare diseases (*Jonathan Watson and Kyriakos S Hatzaras*)

11:10-11:30 From policy to implementation: how to leverage ESIF in support of a National Plan/Strategy for Rare Diseases (*Valentina Bottarelli*)

11:30-12:00 **Discussions and Q&A on Session 3** (*Moderators Domenica Taruscio and Gerhard Steffes*)

**Output of Session 3:** *Concept paper on Opportunities to support RD activities using European Structural Investment Funds.*

#### **12:00-13:00 Lunch**

### **SESSION 4: Consolidating Expert Recommendations in the context of the Delegated Acts** (relates to workshop Question 4)

**13:00-13:45 Discussion Session on 'Preparatory Document to outline the 'Specific Criteria and Conditions' in the field of Rare Diseases''.** Building upon the previous day's sessions, to include the following topics: what is the group consensus regarding readiness for ERNs and main needs of the RD field? What are the participants' comments on the new document? How should it be used? What follow-up discussions/workshops will be needed and what should be the next steps of the Expert Group and the Joint Action? (*Moderators Kate Bushby and Yann le Cam*)

**Output of Session 4:** *Revised 'Document to outline the 'Specific Criteria and Conditions' in the field of Rare Diseases'*

13:45-14:00 Summary of combined next steps and action points (*Domenica Taruscio, Kate Bushby, and Yann Le Cam*)

#### **14:00 Workshop ends**