



## **EPIRARE Workshop**

### **National Registries of Rare Diseases**

*Istituto Superiore di Sanità*

*National Centre for Rare Diseases - Centro Nazionale Malattie Rare (CNMR)*

Rome (Italy)

March 4 and 5, 2014

#### **Provisional Program**

#### **4 March 2014 (ISS - AULA ROSSI) - Via Giano della Bella, 34 - Rome**

- 13:00 Registration and light lunch  
14:00 Scope of the Workshop  
14:30 Registries: a priority for rare disease National Plans (*D. Taruscio*)  
15:00 **Session 1 - Establish a National Registry: the needs, the resources, the opportunities**  
(Working Groups with all participants led by CNMR facilitators). *Pina Frazzica, A. Egle Gentile*  
  
18:00 End of First Day

#### **5 March 2014 (ISS - AULA MAROTTA) - Viale Regina Elena, 299 - Rome**

##### **Session 2 – Current National registries and initiatives**

- 9:00 The French RD Registry. *P. Landais*  
9:15 The Spanish RD Registry. *M. Posada*  
9:30 The Belgian RD Registry. *E. Swinnen*  
9:45 The Italian RD Registry. *D. Taruscio, L. Vittozzi, Y. Kodra*  
10:00 The Finnish Disease registry. *A. Vuori*  
10:15 The Bulgarian RD registries. *R. Stefanov*  
10:30 Preparations for the German Registry. *F. Ueckert*  
10:45 Discussion  
11:00 Break

##### **Session 3 – National Registries and the European perspective**

- 11:30 The views of the EU Commission on National Registries (title TBC) *A. Montserrat*  
11:50 The European Platform on rare diseases registration. *N. Ciaran*  
12:10 The role of National RD Experts and of National RD Registries in the EPIRARE Platform for RD registries. *L. Vittozzi*  
12:30 Lunch  
13:30 Summary of 1<sup>st</sup> day work: The situation and needs in countries which intend to implement a registry  
14:00 General discussion I: Opportunities for cooperation and coordination  
15:00 General discussion II: Capacity building for the implementation of a National Registry  
  
16:00 End of meeting