



EPIRARE Workshop

National Registries of Rare Diseases

*Istituto Superiore di Sanità
National Centre for Rare Diseases - Centro Nazionale Malattie Rare (CNMR)*

Rome, March 4 and 5, 2014

Provisional Program

4 March 2014 - AULA Marotta - Viale Regina Elena, 299 - Rome	
13:00	Registration and light lunch
14:00	Welcome and Scope of the Workshop (<i>D. Taruscio</i>)
14:30	Registries: a priority for rare disease National Plans (<i>D. Taruscio</i>)
15:00	Session 1 - Establish a National Registry: the needs, the resources, the evidences (Working Groups with all participants led by CNMR facilitators). <i>Pina Frazzica, A. Egle Gentile, Rita Ferrelli, Marta De Santis, Sabina Gainotti, Paola Torreri, Yllka Kodra, Pietro Carbone, Marco Salvatore, Luca Ferrari</i>
18:00	End of First Day
5 March 2014 - AULA Marotta - Viale Regina Elena, 299 - Rome	
Session 2 – Current National registries and initiatives (<i>Chair: D. Taruscio; L. Vittozzi</i>)	
8:45	The French RD Registry. <i>P. Landais</i>
9:00	The Spanish RD Registry. <i>M. Posada</i>
9:15	The Belgian RD Registry. <i>E. Swinnen</i>
9:30	The Italian RD Registry. <i>D. Taruscio, L. Vittozzi, Y. Kodra</i>
9:45	The Nordic Rare Disease Registry <i>K. Heimdal</i>
10:00	The Finnish Disease registries. <i>A. Vuori</i>
10:15	The Bulgarian RD registries. <i>R. Stefanov</i>
10:30	Preparations for the German Registry. <i>F. Ueckert</i>
10:45	Discussion
11:00	Break
Session 3 – National Registries and the European perspective (<i>Chair: A. Montserrat; D. Taruscio</i>)	
11:30	The views of the EU Commission on National Registries. <i>A. Montserrat</i>
11:50	The European Platform on rare diseases registration. <i>C. Nicholl</i>
12:10	The role of National RD Experts and of National RD Registries in the EPIRARE Platform for RD registries. <i>L. Vittozzi</i>
12:30	Lunch

13:30	Summary of 1 st 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