



**DATE** 10 - 11 September 2012

**TIME** h 11:45 - 10 September 2012 / h 13:30 - 11 September 2012

**VENUE** Aula Marotta, Italian National Institute of Health - Viale Regina Elena, 299, Rome, Italy

### **OBJECTIVES**

- To share among the participants strengths and weaknesses in developing National Plans and Strategies (NP/NS) on Rare Diseases (RD)
- To identify opportunities for developing NP/NS on RD
- To identify targets and stakeholders of communication for developing NP/NS on RD

### **PROGRAMME**

#### *DAY 1 - 10 September 2012*

11:45 ***Participants registration***

12:00 ***Welcome lunch***

13:00 ***Welcome address***

13:10 ***EUCERD Joint Action: an overview***

Kate Bushby, Stephen Lynn\*

*EUCERD Joint Action Project Leader, Newcastle University, Newcastle upon Tyne*

*\*EUCERD Joint Action Manager, Newcastle University, Newcastle upon Tyne*



- 13:40 **European Project for Rare Diseases Plans Development: from 2008 up to now**  
Domenica Taruscio  
*EUROPLAN Leader, Italian National Institute of Health, Rome*
- 14:10 **EURORDIS activities for National Plans**  
Valentina Bottarelli  
*EURORDIS - European Organisation for Rare Diseases*
- 14:40 **State of art of National Plans for Rare Diseases**  
Edmund Jessop  
*National Commissioning Group – NHS, London*
- 15:00 **Strengths and weaknesses in developing National Plans: results of EUROPLAN 2012-2015 survey**  
Rita Maria Ferrelli  
*EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome*
- 15:20 **Lessons learnt from successes and failures in developing National Plans (group activities)**  
*Facilitators: Amalia Egle Gentile, Marta De Santis, Rita Maria Ferrelli, Domenica Taruscio*  
*EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome*
- 16:50 **Plenary discussion**  
*Chairperson: Rita Maria Ferrelli*  
*EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome*
- 17:40 **How EU can support National Plans on Rare Diseases**  
Antoni Montserrat  
*Health and Consumers General-Directorate (SANCO), European Commission, Luxembourg*
- 18:00 **Closing of the day**





# EUROPLAN

European Project for Rare Diseases National Plans Development  
Project coordinated by the Italian National Centre for Rare Diseases  
Italian National Institute of Health

2012-2015

## INCEPTION WORKSHOP ON NATIONAL PLANNING FOR RARE DISEASES

10-11 September 2012, Rome

### DAY 2 - 11 September 2012

**08:00 Indicators for National Plans**

Domenica Taruscio, Manuel Posada\*, Rita Maria Ferrelli

*EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome*

*\*ISCIII Institute for Rare Diseases Research, Spain*

**09:00 Definition of actions supporting National Plans for Rare Diseases (group activities)**

*Facilitators: Amalia Egle Gentile, Marta De Santis, Rita Maria Ferrelli, Domenica Taruscio*

*EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome*

**10:30 Coffee-break**

**11:00 Plenary feedback**

*Chairperson: Rita Maria Ferrelli*

*EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome*

**12:00 Establishing working groups**

Domenica Taruscio

*EUROPLAN Leader, Italian National Institute of Health, Rome*

**13:00 Financial Issues**

Georgios Margetidis

*Executive Agency for Health and Consumers (EAHC), European Commission, Luxembourg*

**13:30 Closing of the Workshop**



**SCIENTIFIC DIRECTOR** Domenica Taruscio

**SCIENTIFIC SECRETARIAT** Marta De Santis, Rita Maria Ferrelli, Amalia Egle Gentile

**ORGANIZING SECRETARIAT** Giuseppe Bernardo, Stefano Diemoz, Giorgio Vincenti

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