

**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

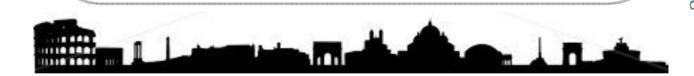
EUROPLAN 2012-2015 Coordinating Team, Italian National Institute of Health, Rome

#### 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





## **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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