

25 March 2013, Rome (Italy)



**DATE** 25 March 2013

**TIME** 09:00 - 18:00

**VENUE** Aula Rossi, Italian National Institute of Health – Via Giano della Bella, 34, Rome, Italy

### OBJECTIVES

- To share the results of both EUROPLAN “A” & “B” processes to select indicators with participants
- To discuss/finalize the Draft EUCERD Recommendation on Indicators for National Plans/Strategies for Rare Diseases
- To discuss/finalize the template for collecting data
- To review/update the full list of Indicators from EUROPLAN I

### PROGRAMME

- 08:30 *Participants registration*
- 09:00 **Welcome and Workshop objectives**  
Domenica TARUSCIO (*EUROPLAN Leader, Rome*)
- 09:20 **Indicators selection according to the Delphi technique (EUROPLAN “A”): presentation of results**  
Rita M. FERRELLI, Amalia Egle GENTILE, Marta DE SANTIS (*EUROPLAN Coordinating Team, Rome*)
- 09:40 **Indicators “cross-over” selection according to the EURORDIS approach (EUROPLAN “B”): presentation of results**  
Valentina BOTTARELLI (*EURORDIS Team, Brussels*)
- 10:00 **Presentation of Draft EUCERD Recommendation on Core Indicators for National Plans/Strategies for Rare Disease**  
Yann LE CAM (*EUCERD Vice-Chair, Paris*)
- 10:20 **Discussion of the final selection/final wording of about 20 main Indicators for National Plans/Strategies for Rare Diseases”**  
*Moderators:*  
Domenica TARUSCIO (*EUROPLAN Leader, Rome*), Yann LE CAM (*EURORDIS Leader, Paris*)
- 11:30 *Coffee-break*
- 11:45 **Share/finalize the Template for data collection based on Indicators**
- 13:30 *Lunch*
- 14:30 **Review/update of the full list of Indicators from EUROPLAN I**
- 16:30 *Coffee-break*
- 17:00 **Conclusions**  
Domenica TARUSCIO (*EUROPLAN Leader, Rome*), Yann LE CAM (*EURORDIS Leader, Paris*)
- 17:30 **EUROPLAN National Conferences and post-NCs’ activities in support to Member States**  
EURORDIS Team - EUROPLAN Team
- 18:00 *End of Workshop*



**SCIENTIFIC DIRECTOR** *Domenica Taruscio*

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

**ORGANIZING SECRETARIAT** *Linda Agresta, Giuseppe Bernardo, Patrizia Crialesi, Giorgio Vincenti*

