

EUROPLAN Post-National Conference Activities

“DEBRIEF SESSION”

EUROPLAN National Conference

EURORDIS Advisor	Simona BELLAGAMBI
National Alliance	UNIAMO FIMR
NA Contact person	Renza BARBON GALLUPPI (President)
Date	28/01/2014
Place	Rome
Country	Italy
Program	Annex I – Program (Italian version)
Official Conference Report	Forthcoming
Notes	<i>The National Conference (NC) aimed to provide a synergistic opportunity in support of the process of approving the National Plan for Rare Diseases 2013-2016. It involved more than 160 people, comprising all stakeholder representatives. A series of preparatory meetings were carried out: April 23, 2013, May 21, 2013, June 25, 2013, September 9, 2013 and 17/21 February 2014 at the Ministry of Health, Rome.</i>

“DEBRIEF SESSION”

Date	28/01/2014
Place	Rome (<i>Ministry of Health</i>)
Time	16:00 – 18:00 (<i>local time</i>)
Object	To identify needs, opportunities and measures to develop further the National Rare Disease Plan or Strategy, consolidating and improving the fieldwork in the NCs and the local human resources.
Participants	
<i>EUROPLAN Coordinating Team member/s</i>	Domenica TARUSCIO, Marta DE SANTIS, Pina FRAZZICA,
<i>EURORDIS Advisor</i>	Simona BELLAGAMBI
<i>EUCERD Joint Action member</i>	Victoria HEDLEY
<i>MoH Representatives</i>	Maria Elena CONGIU
<i>National Alliance Representative</i>	Renza BARBON GALLUPPI
<i>Representatives from</i>	Paola FACCHIN (Permanent Technical Interregional Coordination)

<i>high-level institutions</i>	Table)
	Emanuela REALE (National Agency for Regional Health Services - AGENAS)
	Valentina BOTTARELLI (EURORDIS)
	Luisa MUSCOLO and Daniela SETTESOLDI (Italian medicines agency – AIFA)
	Paola TORRERI (Italian National Centre for Rare Diseases Italian National Institute of Health)
	Bianca PIZZERA (Italian Association for Primary Immunodeficiencies)
	Astolfo ROMANO (Sinodè ¹)
<i>Notes</i>	

¹ Sinodè is a consultancy agency that try to support private and public organisations that work in welfare system