

*EUROPLAN Post-National Conference Activities*

**“DEBRIEF SESSION”**

**EUROPLAN National Conference**

EURORDIS Advisor	Simona BELLAGAMBI (UNIAMO FIMR)
National Alliance	FEDER (Federación Española de Enfermedades Raras)
NA Contact person	Juan CARRION (President); Alba ANCOCHEA (Director)
Date	21/11/2014
Place	Madrid
Country	Spain
Program	Annex I – Program (Spanish version)
Official Conference Report	Forthcoming

*Notes*

*The second Spanish National Conference on Rare Diseases, organised by the Spanish National Alliance FEDER, took place in Madrid on 20 and 21 November 2014. Participants to the conference were structured into 10 working groups (WG):*  
*Group 1: Governance and monitoring of the National Plan; Group 2: Definition, coding and recording of RD; Group 3: Information and training on RD; Group 4: Research; Group 5: Centres, Services and Units of Reference; Group 6: Healthcare Model; Group 7: Orphan drugs and health products; Group 8: Social Services, helpline, disability; Group 9: Work inclusion; Group 10: Educational Inclusion.*  
*The WGs altogether involved more than 140 stakeholders, representing the main sectors linked to rare diseases.*  
*The aim of this conference was to collect the proposals and recommendations of the working groups on each of the above issues related to rare diseases and present them to the competent bodies for possible adoption and implementation.*

**“DEBRIEF SESSION”**

Date	21/11/2014
Place	Madrid ( <i>Ministry of Health, Social Services and Equality</i> )
Time	13.30-15.00 ( <i>local time</i> )
Object	To identify needs, opportunities and measures to develop further the National Rare Disease Strategy, consolidating and

	improving the fieldwork in the National Conferences and the local human resources.
<b>Participants</b>	
<i>EUROPLAN Coordinating Team member/s</i>	Marta DE SANTIS
<i>EURORDIS Advisor</i>	Simona BELLAGAMBI
<i>EUCERD Joint Action member</i>	Victoria HEDLEY
<i>MoH Representatives</i>	Paloma Casado DURANDEZ ; Pilar SOLER CRESPO
<i>National Alliance Representative</i>	Juan CARRION (President of FEDER); Alba ANCOCHEA (Director of FEDER)
<i>Representatives from high-level institutions</i>	Elena DULÍN-IÑIGUEZ (AECNE - Spanish Association for Neonatal Screening)
	Manuel POSADA DE LA PAZ (Commission Expert Group on Rare Diseases)
	Roser VALLES (Government of Catalonia - General Director for Health Ordinance and Regulation)
	Maria Luisa ARTEGOITIA GONZALEZ (Basque Country Director of Planning, Management and Health Regulations -)
	Rafael CAMINO (Representative in the National Strategy on RD-Andalusian Autonomous Government)
	Angel ABAD REVILLA (Madrid Autonomous Community)
	Terkel ANDERSEN (EURORDIS President)
	Yann Le Cam (EURORDIS Chief Executive Officer)
Valentina Bottarelli (EURORDIS - EU Public Affairs Senior Advisor)	
<b>Notes</b>	