




## EUROPLAN Post-National Conference Activities

### “DEBRIEF SESSION”

 National Conference	
EURORDIS Advisor	
National Alliance	
NA Contact person	
Date	
Place	
Country	
Program	
Report	
Notes	

“DEBRIEF SESSION”	
Date	
Place	
Time	<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</i>
	<i>Coordinating Team member/s</i>
	<i>EURORDIS Advisor</i>
	<i>EJA Newcastle Team member</i>
	<i>MoH Representative</i>
	<i>National Alliance Representative</i>
	<i>Other/s</i>
Notes	
Annexes	



AREAS	MAIN NEEDS/GAPS for which require the EUROPLAN “A” technical support (starting from strengths and weaknesses)
<p><b>AREA 1</b>  <b>Plans and Strategies in the Field of Rare Diseases</b></p> <ul style="list-style-type: none"> <li>• <i>Development of Regulations/Laws</i></li> <li>• <i>Establishment of Coordination mechanisms</i></li> <li>• <i>Establishment of an external evaluation of the plan/strategy procedure</i></li> <li>• <i>Degree of comprehensiveness</i></li> <li>• <i>Establishing of a budget for developing the plan/strategy</i></li> </ul>	
<p><b>AREA 2</b>  <b>Adequate Definition, Codification and Inventorying of Rare Diseases</b></p> <ul style="list-style-type: none"> <li>• <i>To officially adopt the EC RD definition (No more than 5 cases / 10,000 inhabitants)</i></li> <li>• <i>To include the best RD diseases classification currently existing into the public health care related services</i></li> <li>• <i>Defining a surveillance system based on a patient outcomes registry</i></li> </ul>	
<p><b>AREA 3</b>  <b>Research on rare Diseases</b></p> <ul style="list-style-type: none"> <li>• <i>Building a research programmes for RD</i></li> <li>• <i>Existence of national policy in support of the recruitment of young researchers/scientists specifically for rare diseases</i></li> <li>• <i>Allocate funds for the RD research programme</i></li> </ul>	
<p><b>AREA 4</b>  <b>Centres of Expertise and European Reference Networks for Rare Diseases</b></p> <ul style="list-style-type: none"> <li>• <i>Improve the quality of health</i></li> </ul>	



*care by defining appropriate centres with experience on RD as well as pathways that reduce the diagnosis delay and facilitate the best both cares and treatments to patients*

## AREA 5

### Gathering the Expertise on rare Diseases at European Level

- *Existence of a information sites for professionals provided by the plan/strategy*
- *Promoting training activities and awareness educational campaigns among professionals*
- *Develop screening policies*
- *Ensure quality of RD diagnosis laboratory*
- *Ensure the mechanism that facilitates ODD access and the reimbursement of their cost to patients after they got the market authorization by EMEA.*
- *To develop mechanism to accelerate ODD availability*

## AREA 6

### Empowerment of Patients' Organisations

- *Promoting the existence of a RD patients' organizations that represent all RD patient associations*
- *Patients' organizations involvement in decisions affecting RD*
- *Support the activities performed by including patient organizations, such as awareness raising, capacity-building and training, exchange of information and best practices, networking, outreach to very isolated patients*
- *Building - supporting the existence of comprehensive help line and information sites for patients provided by the plan/strategy*

- *Compensating disabilities caused by rare diseases*
- *Supporting social services aimed at rare disease patients and their families*
- *Supporting rehabilitation programmes*

## AREA 7

### Sustainability

- *Ensure through appropriate funding mechanisms the long-term sustainability of infrastructures developed in the field of information, research and healthcare for rare diseases*
- *Cooperate with other Member States to address the need for sustainability of European-wide research infrastructures, common to all Member States and common to the highest possible number of rare diseases*