EUROPLAN
European Project for Rare Diseases National Plans Development
Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health
2012-2015

EUCERD Joint Action
Co-funded by the European Commission
Executive Agency for Health and Consumers

EUROPLAN National Conferences and

Post-NCs' activities in support to Member States

Yann Le Cam, Ariane Weinman,
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EURORDIS Team

Paris, France
Brussels, Belgium

EUROPLAN "B"

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EUROPLAN 2012-2015 Coordinating Team

Italian National Centre for Rare Diseases
Italian Institute of Health
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EUROPLAN "A"

EUROPLAN Debrief Sessions post-National Conferences

Why?

OBJECTIVES:

- To identify and collect needs, challenges and the most pressing issues emerged during the EUROPLAN NC in relation to the development of RD National Plans and Strategies;
- To suggest dedicated solutions to national authorities.

LONG TERM OBJECTIVE:

- To create a "hub" within the ISS-EUROPLAN team for support and information for national authorities on NP/NS, based on the expertise built from the direct contacts with national authorities.

EUROPLAN Debrief Sessions post-National Conferences

Who?

1/2 EUROPLAN

Coordinating Team member/s

(who participate/s to the NC)

1 EURORDIS Advisor

1 EJA Coordination representative

1/2 MoH representatives

(and key persons involved in elaboration/implementation of NP, including contact person of EUROPLAN "A", identified in collaboration with EURORDIS and NA)

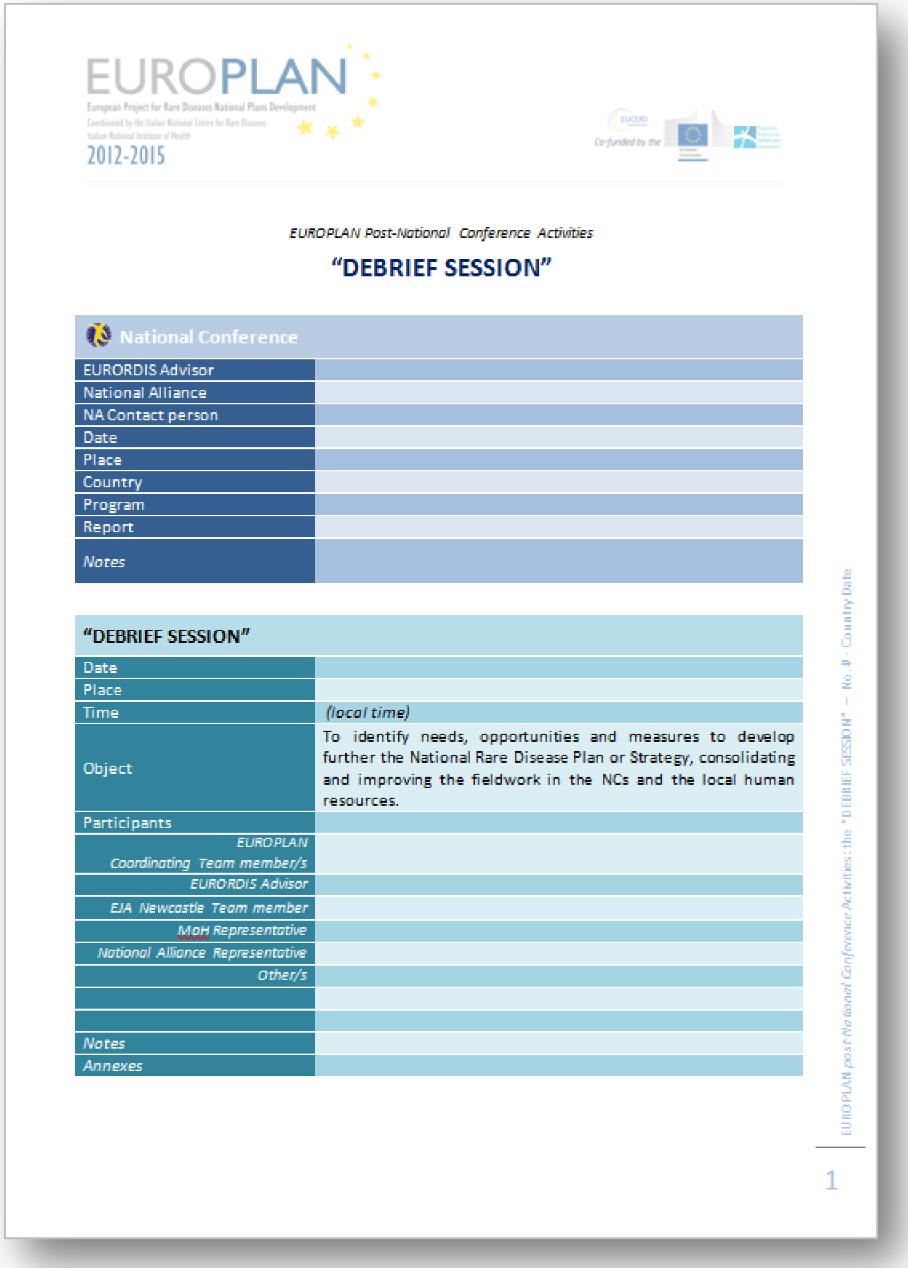
How?

INSTRUMENTS and RESULTS:

A <u>common form</u>
will be used to identify the MAIN NEEDS/GAPS for which the Country (MoH Representative)

requires

the EUROPLAN "A" technical support
(starting from strengths and weaknesses looked during the NC)



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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	*(local time)*
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	
EUROPLAN Coordinating Team member/s	
EURORDIS Advisor	
EJA Newcastle Team member	
MoH Representative	
National Alliance Representative	
Other/s	
Notes	
Annexes	

EUROPLAN post-National Conference Activities: the "DEBRIEF SESSION" – No. # - Country Date

1

EUROPLAN Debrief Sessions post-National Conferences

When?

- At the end of the EUROPLAN National Conference.
- For approximately 1 hour or 1 ½ hour.

EUROPLAN Debrief Sessions post-National Conferences

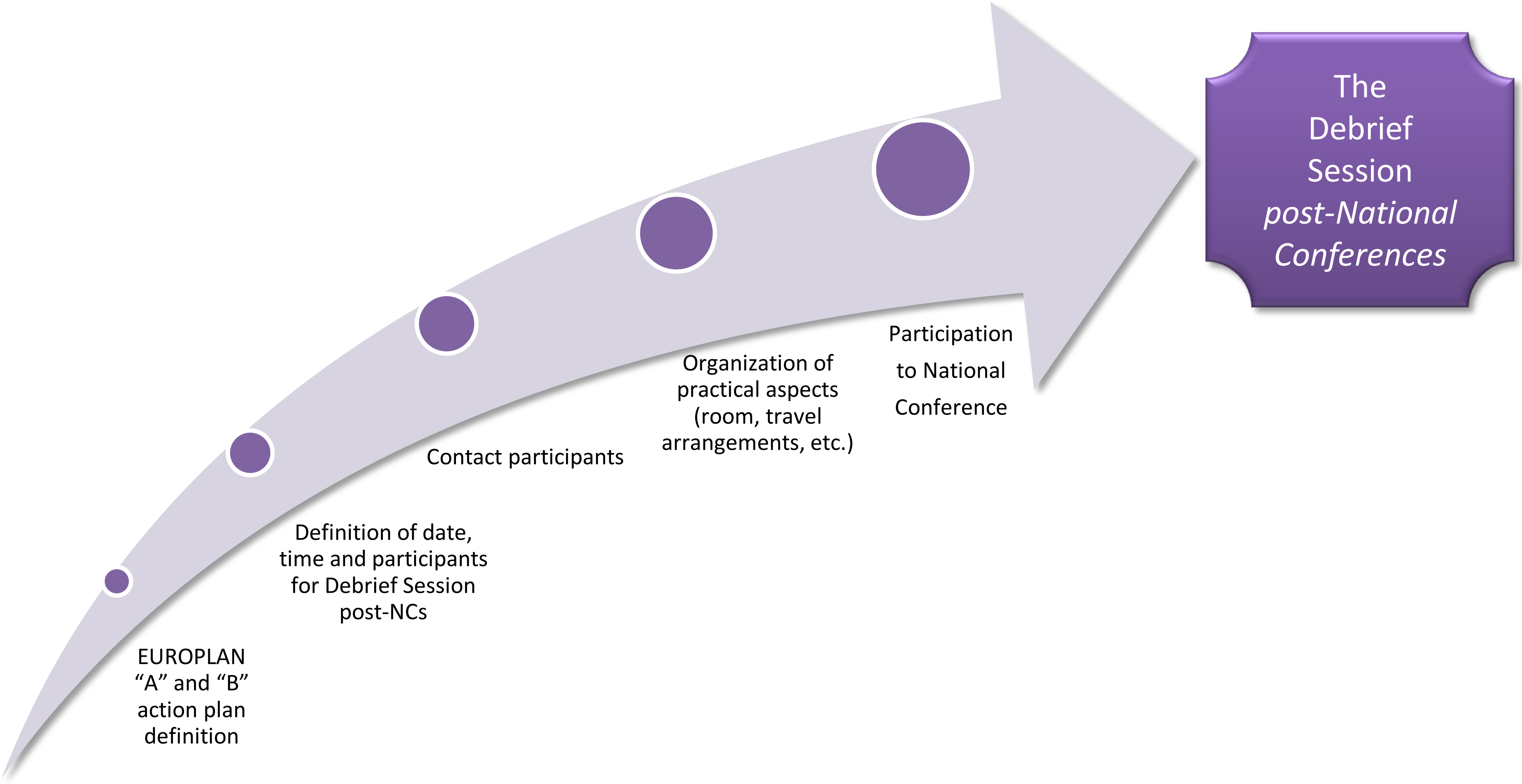
Where?

In each EU MS where a EURORDIS NC will be organised, starting from February 2013.

NCs in EU MS *starting from February2013*

#	EU MS selected for NCs	Date	Organiser	EURORDIS Advisor
1	**SLOVAKIA**	**27-28 February 2013**	Slovak Alliance of Rare Diseases	Dorica Dan
2	**ROMANIA**	**24-25 May 2013**	RONARD; Romanian Alliance for Rare Diseases	Dorica Dan
3	**FINLAND**	**June 2013**	Finnish Rare Diseases Alliance	Maria Gardsäter
4	**CYPRUS**	**End of June 2013**	CARD; Cyprus Alliance for Rare Disorders	Lily Cannon
5	**ITALY**	**26 September 2013**	UNIAMO; Italian Federation for Rare Diseases	Simona Bellagambi
6	**POLAND**	**26-28 September 2013**	ORPHAN	Vlasta Zmazek
7	**FRANCE**	**24 October 2013** *(assessment II NP)*	Alliance Maladies Rares	Christel Nourissier
8	**HUNGARY**	**25-26 October 2013** (tbc)	HUFERDIS; Hungarian Federation of People with Rare and Congenital Diseases	Dorica Dan
9	**LITHUANIA**	**14 November 2013** (tbc)- During Lithuania EU Presidency	Ministry of Health	Yann Le Cam/ Valentina Bottarelli
10	**LUXEMBOURG**	**20 November 2013**	ALAN; Luxembourg Alliance for Rare Diseases and Neuro Muscular Diseases	Lily Cannon
11	**CROATIA**	**End 2013**	Croatian Alliance for Rare Diseases	Vlasta Zmazek
12	**IRELAND**	**2013** (date tbc)	GRDO, GENETIC AND RARE DISORDERS ORGANISATION	Avril Daly
13	**NETHERLANDS**	**7-8 November 2013**	VSOP; the Dutch Genetic Alliance	Melissa Hillier
14	**PORTUGAL**	**2013** (date tbc)	APADR; Portuguese Alliance of Rare Disease Patient Organisations	Lene Jensen
15	**DENMARK**	**Early 2014**	RDD; Rare Disorders Denmark	Lene Jensen
16	**SPAIN**	**Early 2014**	FEDER; the Spanish Alliance for Rare Diseases	Simona Bellagambi
17	**BELGIUM**	28 February 2014	RaDiOrg.be; Belgian National Alliance for Rare Diseases	Lene Jensen

STEPS TO ORGANIZE the Debrief Sessions post-NCs



EUROPLAN “A” and “B” action plan definition

Definition of date, time and participants for Debrief Session post-NCs

Contact participants

Organization of practical aspects (room, travel arrangements, etc.)

Participation to National Conference

The Debrief Session *post-National Conferences*

EUROPLAN Debrief Sessions post-National Conferences

Follow-up

The EUROPLAN Coordinating Team,
according to identified needs and the existing resources
- in collaboration with EURORDIS and the National Alliances and EJA Coordination-,
will arrange for each Country **A DEDICATED SOLUTION**
in order to provide
connections to experts in other Countries (with same solved problems)
and **existing "guidance" documents** (e.g. EUCERD Reports, Recommendations, etc.)
regarding identified needs.

Specific instruments and methods (e.g. conference calls, Skype-calls, workshops)
will be selected considering the individual cases.

EUROPLAN Debrief Sessions post-National Conferences

Debrief Session No. 0 - Slovak Republic, 28.02.2013

National Conference	
EURORDIS Advisor	Dorica DAN
National Alliance	Slovak RD Alliance, DebRA Slovak Republic
NA Contact person	Beata RAMLJAKOVA
Date	27 – 28 February 2013
Place	Bratislava
Country	Slovak Republic
Program	• Annex I (27.02.2013 - Press Conference and Office Meeting Interdipartimental working group of MoH for RD) • Annex II (28.02.2013 - National Conference)
Report	*Date to define*
Notes	• *First NC* • *The format of the Conference is different: no parallel sessions*

EUROPLAN Debrief Sessions post-National Conferences

Debrief Session No. 0 - Slovak Republic, 28.02.2013

"DEBRIEF SESSION"	
Date	28 February 2013
Place	Bratislava
Time	16:00 -16:30 *(local time)*
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	
EUROPLAN Coordinating Team member/s	Amalia Egle GENTILE
EURORDIS Advisor	Dorica DAN
EJA Newcastle Team member	Victoria HEDLEY
MoH Representative	Frantisek Cisarik
National Alliance Representative	Beata RAMLJAKOVA
Other/s	Janette FARTELOVA, Genzyme
	Tatiana FOLTANOVA, Comenius University
Notes	
Annexes	

EUROPLAN Debrief Sessions post-National Conferences

Debrief Session No. 0 - Slovak Republic, 28.02.2013

AREAS	**MAIN NEEDS/GAPS** **for which require the EUROPLAN “A” technical support** (starting from strengths and weaknesses)
AREA 1 **Plans and Strategies in the Field of Rare Diseases** • *Development of Regulations/Laws* • *Establishment of Coordination mechanisms* • *Establishment of an external evaluation of the plan/strategy procedure* • *Degree of comprehensiveness* • *Establishing of a budget for developing the plan/strategy*	They have a strategy already approved which they are turning into a NP. They have established a coordination team for this process . This will between interdepartmental and interministerial. No budget as yet. They will send us the officially approved English translation of their strategy, to publish on EUROPLAN and EUCERD websites. The WG are meeting in April, June and September and plan to get the plan approved in December. We will send a proposal before April meeting to FC, to suggest areas for collaboration/debate with other countries or experts, if useful to them.
AREA 2 **Adequate Definition, Codification and Inventorying of Rare Diseases** • *To officially adopt the EC RD definition (No more than 5 cases / 10,000 inhabitants)* • *To include the best RD diseases classification currently existing into the public health care related services* • *Defining a surveillance system based on a patient outcomes registry*	They have used EU definition for a RD Are talking about using Orphacode and OMIM but raised difficulties of persuading clinicians to enter data, as always. They do feel they need to focus on Registries, **CoE** and ERNs due to the Cross-Border Healthcare Directive.

EUROPLAN Debrief Sessions post-National Conferences

Debrief Session No. 0 - Slovak Republic, 28.02.2013

AREAS	**MAIN NEEDS/GAPS** **for which require the EUROPLAN "A" technical support** (starting from strengths and weaknesses)
AREA 3 **Research on rare Diseases** - *Building a research programmes for RD* - *Existence of national policy in support of the recruitment of young researchers/scientists specifically for rare diseases* - *Allocate funds for the RD research programme*	They have discussed difficulties emerging from fact the MoH des not provide financial resources for research. Difficult to implement EU projects due to co financing requirement and advance payment required.
AREA 4 **Centres of Expertise and European Reference Networks for Rare Diseases** - *Improve the quality of health 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*	CoE and ERNs are two of their key priorities, especially because of the CBHC Directive. They share experiences with the Czech Republic and have trust especially in Milan Macek. Concern around criteria they will use – some seem in favour of using EUCERD Recs, others mentioned only 3 key Orphanet criteria would be best start. We tried to stress importance of continuity of care and added that if you start too low, impact will be negligible. We stressed need for multidisciplinarity too. They were keen to encourage each other to make what is there much more visible e.g. via Orphanet and State of the Art.

EUROPLAN Debrief Sessions post-National Conferences

Debrief Session No. 0 - Slovak Republic, 28.02.2013

AREAS	**MAIN NEEDS/GAPS** **for which require the EUROPLAN "A" technical support** (starting from strengths and weaknesses)
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*	They have a National Health Information Centre which actually operates most of their national health registries including rare diseases registries. No Help line – patient reps want some, and free of charge Clinical guidelines? For PAH there are some, via European Society of Cardiology. NBS is excellent and well-established. And well promoted! Quality of labs – not discussed. They have same market authorisation as other countries. Usual issue about local access and affordability. Don't have a rep on the COMP currently but they are pressing the MoH for this. They discussed a mechanism for acc. ODD availability and are familiar with CAVOMP IF.
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*	The Slovak National Alliance for RD is active at national and EU levels, despite being very new! They are not involved in the decisions. They organized RDD campaign which is major awareness-raising and they are using their website after this conference to update on NP development situation. Through this conference and other meetings they improve their organisational capacity. Social resources – provided by disability degree. No mention of rehabilitation centres. No funding for spa.

Debrief Session No. 0 - Slovak Republic, 28.02.2013

AREAS	MAIN NEEDS/GAPS for which require the EUROPLAN "A" technical support (starting from strengths and weaknesses)
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*	No support centrally here No

EUROPLAN Debrief Sessions post-National Conferences

Debrief Session No. 0 - Slovak Republic, 28.02.2013

Follow-up

The EUROPLAN Coordinating Team,
according to identified needs and the existing resources
- in collaboration with EURORDIS and the National Alliances and EJA Coordination-,
will arrange for the Slovak Republic **A DEDICATED SOLUTION**
in order to provide
connections to experts in other Countries (with same solved problems)
and **existing "guidance" documents** (e.g. EUCERD Reports, Recommendations, etc.) regarding identified needs:
Centres of Expertise, ERNs and Registries.

Specific instruments and methods (e.g. conference calls, Skype-calls, workshops)
will be selected considering this case.