



**PLENARY 30 May 2015**

Inspiration from national conferences: an overview of successes in national rare disease strategies



# SHAPING EU RARE DISEASE POLICY

- **Communication from the European Commission** to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions : « **Rare Diseases: Europe's Challenge** » **11 November 2008**
  - First comprehensive policy text addressing issues faced by RD patients, from research on RDs, to diagnosis, access to care and adapted services and development of training, education, awareness on RDs
- **Council Recommendation on an Action in the field of Rare Diseases, 8 June 2009**
  - Adopted by EU Ministers of Health
  - **Promote the adoption of RD National Plan/Strategy in EU MS**
  - Creation of the European Union Committee of Experts on Rare Diseases (EUCERD) in November 2009
  - Replaced by the European Commission Expert Group on Rare Diseases in July 2013

# THE IMPLEMENTATION OF THAT POLICY HAS BEEN MONITORED BY THE EC FIVE YEARS AFTER, IN 2014



## **Implementation report on the Commission Communication on Rare Diseases: Europe's challenges and Council Recommendation of 8 June 2009 on an action in the field of rare diseases**

**Jarosław Waligóra**

DG Health and Consumers, European Commission

# RD NATIONAL PLANS/STRATEGIES

MAY 2015



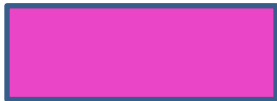
**21** EU MS with RD Plan/ Strategy



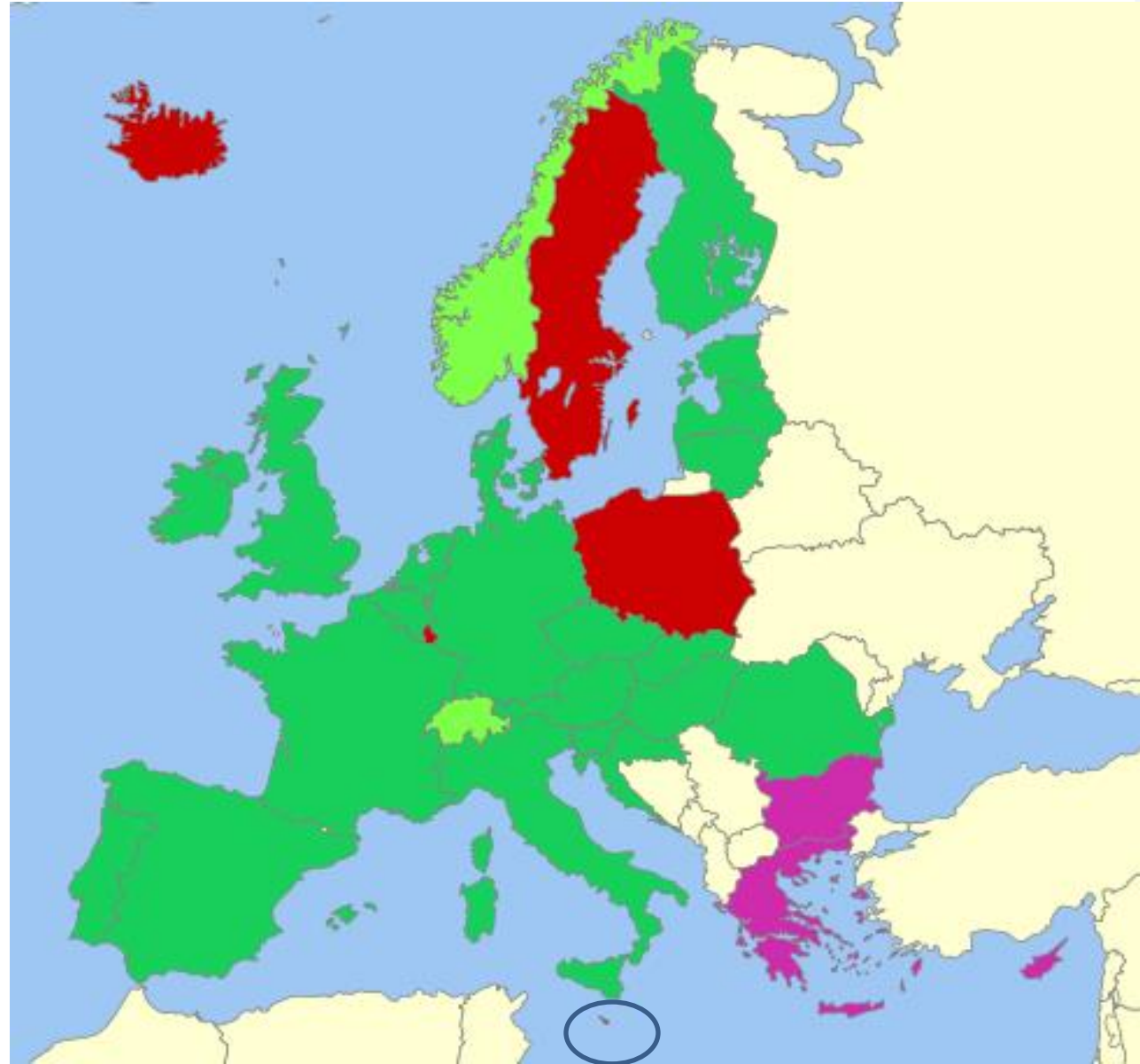
Switzerland + Norway with RD Plan/ Strategy



**4** EU MS + Iceland with no RD Plan



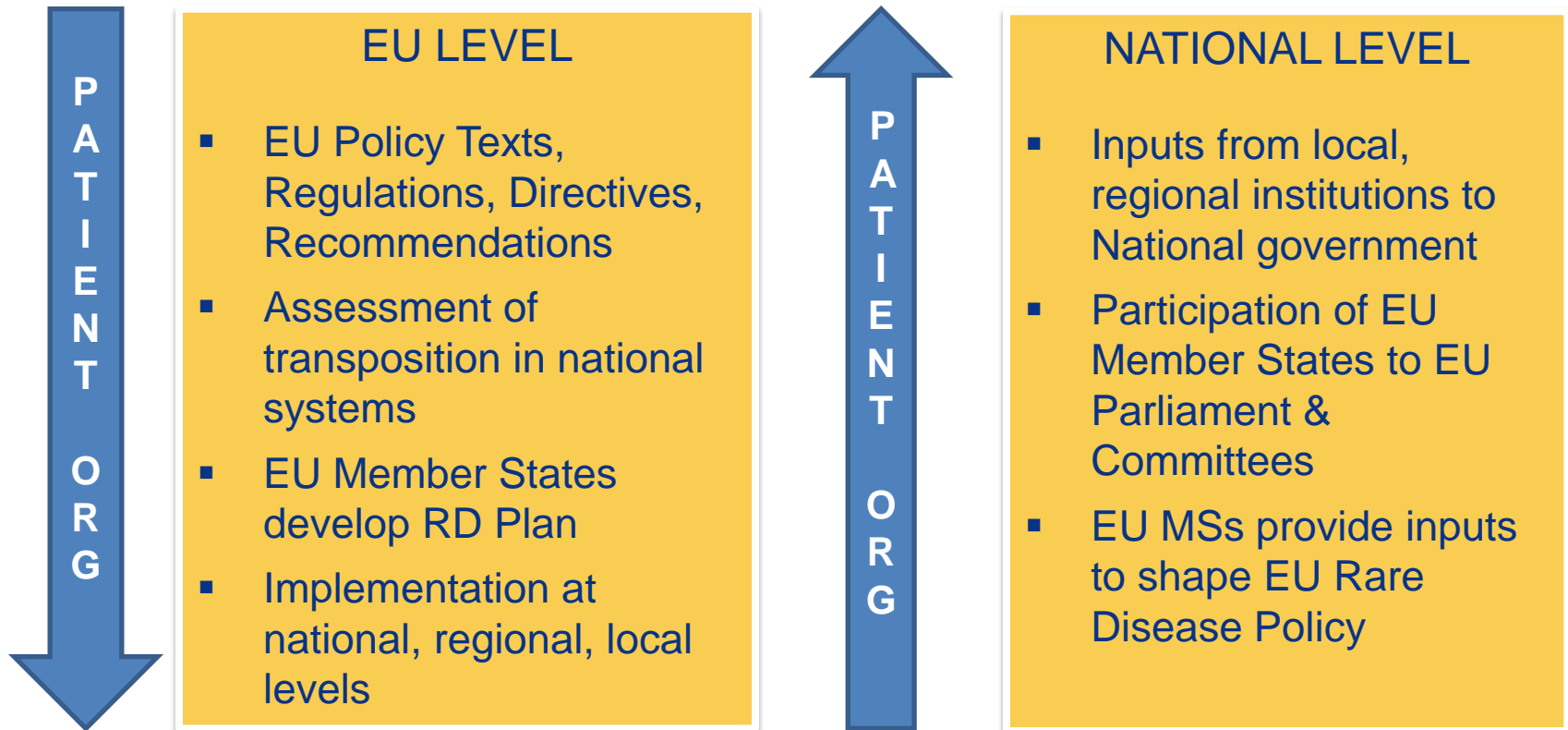
**3** EU MS (Bulgaria, Cyprus, Greece) :  
1st RD Plan ended  
(discussion ongoing for continuity)



**EU 28 + ICELAND, NORWAY, SWITZERLAND**

**The development of national plans for rare diseases in Europe is the result of a two-way communication between the European level and the national level**

**EURORDIS, National Alliances and RD patient organisations are active at all levels**





# 25 CONFERENCES OVER 2012 - 2015

## EUROPLAN National Conferences 2012-2015



On this map you can find when and where the EUROPLAN National Conferences are being held and details about the organisers, in most cases National Alliances (NA) of Rare Disease patient organisations.

- [Final report of each EUROPLAN National Conference](#)



21 National Conferences  
in EU + 4 in Europ. countries

- Austria**
  - Belgium**
  - Croatia**
  - Cyprus**
  - Denmark**
  - Finland**
  - France**
  - Greece**
  - Hungary**
  - Ireland**
  - Italy**
  - Lithuania**
  - Luxembourg**
  - Netherlands**
  - Poland**
  - Portugal**
  - Slovakia**
  - Romania**
  - Spain**
  - Sweden**
  - UK**
- +  
**Georgia**  
**Serbia**  
**Russia**  
**Ukraine**

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## 1 Common Strategy

- Integrated EU / National
- Comprehensive
- Longterm
- Multi-skateholders

## 1 Common Format

- Patient-led
- Workshops on 6 main themes
- Highlights on national pressing needs
- Outcomes oriented/  
Concrete proposals
- **Final Reports** (common template)

1. Methodology and Governance of a NP
2. Definition & inventorying (Information & Training)
3. Research on RD
4. Care: Centres of Expertise & EU Reference Networks
5. Orphan Drugs
6. Social Services for RD

Same themes as in:



National Conferences  
Content Guidelines  
and  
EUCERD  
Recommendations

EUROPLAN II NC  
Workshops

2009 EU Council  
Recommendation

EUCERD Core  
Indicators

EUROPLAN I  
Recommendations



# EUROPLAN NATIONAL CONFERENCES

## 21 REPORTS PUBLISHED

[WWW.EURORDIS.ORG/CONTENT/REPORTS-EUROPLAN-NATIONAL-CONFERENCES-2012-2015](http://WWW.EURORDIS.ORG/CONTENT/REPORTS-EUROPLAN-NATIONAL-CONFERENCES-2012-2015)



# KEY ACHIEVEMENTS

- EUROPLAN NATIONAL CONFERENCES are acknowledged being an excellent forum:
  - To gather all relevant parties in order to reinforce the dialogue amongst them;
  - To discuss and come up together with concrete proposals on all issues addressed in the Council Recommendation;
  - To discuss together the orientations of the National Plan/Strategy on Rare Diseases and its implementation.

## KEY FACTS & FIGURES

- 25 EUROPLAN National Conferences in 21 EU MS + 4 other European countries from 2012 – 2015 (EUCERD Joint Action)
- 10 EURORDIS-EUROPLAN Advisors supervising the organisation of 2 or 3 Conferences each
- Above **3000 participants in total**
  - 32% Patient representatives
  - 31% Healthcare professionals
  - 14% Public authorities and politicians
  - 9% Academics and researchers
  - 9% Industry
  - 5% Other (insurers, social workers, media...)

**National Alliances still need**

**“strong and common advocacy tools”**

**to promote the good measures to be  
adopted and implemented in their country  
in each of the 6 themes addressed in the  
EUROPLAN conference**

## How EURORDIS and EUROPLAN Advisors can help?

- Proposal to identify **1) good practices & 2) inspiring proposals** on governance, research, access to care (CEs & ERNs), orphan drugs and social care  
from **Europlan Conference Reports + current RD National Plans + State of the Art on RDs, others...**
- **Ongoing work:** to be discussed at this Membership Meeting
- **Collective work:** Good Practices & Inspiring proposals reviewed by National Alliances / members

**Will inform the implementation phase of RD Plans**