

# EUROPLAN

European Project for Rare Diseases National Plans Development



## **Recommendations to support rare diseases National Plans and Strategies**

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# Council Recommendation

of June 2009

on an action in the field of rare diseases (2009/C 151/02)

## ... RECOMMENDS THAT MEMBER STATES:

- a) **elaborate and adopt a plan or strategy as soon as possible, *preferably by the end of 2013 at the latest***, aimed at guiding and structuring all relevant actions in the field of rare diseases within the framework of their health and social systems
- b) **take action to integrate current and future initiatives at local, regional and national levels** into their plans or strategies **for a comprehensive approach**
- c) **define a limited number of priority actions** within their plans or strategy, **with objectives and follow-up mechanisms**
- d) **Take note of the development of guidelines and recommendations** for the elaboration of national action for rare diseases by relevant authorities at national level in the framework **of the ongoing european project for rare diseases national plans development (EUROPLAN)...**



# EUROPLAN

**It's a three year (2008-2011) project** funded by the EU Commission

(Programme of Community action in the field of Public Health, 2003 - 2008)

**Co-ordinator:** Dr. Domenica Taruscio – Director of the National Centre for Rare Diseases (Istituto Superiore di Sanità, Italy)

**Organisation:**

**The project include 8 work packages:**

- **WP1 - WP3** deal with the management of the project and the dissemination of the results
- **WP4 - WP8** are the core WPs

The Coordinator is supported by the **Steering Committee** and the **Advisory Committee**

**Partners:** 31 Countries and EURORDIS



# EUROPLAN

## Main goals:

**Develop recommendations** for the elaboration of a national plan or strategy for rare diseases

**Elaborate indicators** for monitoring national plans/strategies

**Discuss the recommendations** with stakeholders

**Disseminate** the EUROPLAN recommendations

***Focusing on the already available MS experiences on RD, EUROPLAN will contribute to share information, models and data on effective strategies***



# EUROPLAN: an inclusive project

- Associated partners

Institution	Country
Istituto de Salud Carlos III	<u>Spain</u>
University of Tartu	<u>Estonia</u>
European Organisation for Rare Diseases ( <u>Eurordis</u> )	
The Netherlands Organisation for Health Research and Development – Steering Committee on Orphan Drugs	The Netherlands
<u>Karolinska Institutet</u>	<u>Sweden</u>
Istituto di Ricerche <u>Farmacologiche</u> Mario Negri	<u>Italy</u>
Bulgarian Association for Promotion of Education and Science	<u>Bulgaria</u>
London Strategic Health Authority	<u>UK</u>
Fundacion Canaria de Investigacion y Salud	<u>Cruz de Tenerife, Spain</u>

- Collaborating partners

Institution	Country
Federal Ministry of Health	<u>Germany</u>
Ministry of Health - Health Care Organisation Department	<u>France</u>
<u>Italian Ministry of Health</u>	<u>Italy</u>
The National Health Service	<u>Greece</u>
National Organisation for Medicines	<u>Sweden</u>
<u>Läkemedelsverket</u>	<u>Italy</u>
Ospedale S. Giovanni Bosco - <u>Clinical Research Center for RD</u>	<u>Portugal</u>
Hospital Dom Estefania	<u>Czechia</u>
Children's University Hospital Zagreb	<u>Malta</u>
Mater Dei Hospital	<u>Cyprus</u>
The Cyprus Institute of Neurology & Genetics	<u>Czech Republic</u>
University Hospital of Motol	<u>Turkey</u>
Department of Medical Biology, <u>Academy of Sciences</u>	<u>Hungaria</u>
Faculty of Health Sciences, <u>University Pecs</u>	<u>Italy</u>
La Sapienza University	<u>Italy</u>
EUROCAT	<u>Italy</u>
<u>Epidemiology Unit - Istituto Nazionale</u>	<u>Spain</u>
Fundació Doctor Robert	<u>Finland</u>
The Family Federation of Finland	<u>USA</u>
Office for Rare Diseases, National Institute of Health	

Health authorities & health care planners

Clinicians, health and social operators

EURORDIS patients' groups

Scientists





# AN Partners



# EUROPLAN

## SPECIFIC OBJECTIVES

- ✓ **Collect information on EU Member States initiatives and experiences on rare diseases**
- ✓ **Develop the recommendations for the elaboration of a national plan or strategy for rare diseases (WP7)**
- ✓ **Develop indicators for monitoring the implementation and evaluating the impact of National Plans or strategies for RD (WP5)**

***It's working capitalising the existing efforts and experiences, avoiding duplication of activities and strengthening possible synergies among RD community***



# European Project for Rare Diseases National Plans Development (EUROPLAN)

## Up to now we have elaborated:

- A) Document “**Recommendations for the development of National Plan or Strategies for rare diseases. *Guidance Document***”
- The document has been prepared by:
- **WP7 leader** (The Netherlands Organisation for Health Research and Development (ZonMw) - Steering Committee on Orphan Drugs, Netherlands)
  - **the Coordination EUROPLAN team**
  - with the contribution of several **other EUROPLAN partners and experts**
- B) Document “**Indicators for monitoring national plans/strategies**”
- The document has been prepared by:
- **WP5 leader** (Rare Diseases Research Institute - Instituto de Salud Carlos III (Madrid, Spain)
  - Europlan Working Group on Indicators
  - **the Coordination EUROPLAN team**





# EUROPLAN DEFINITION OF A NATIONAL PLAN OR STRATEGY

***a set of integrated and comprehensive health and social policy actions for rare diseases***

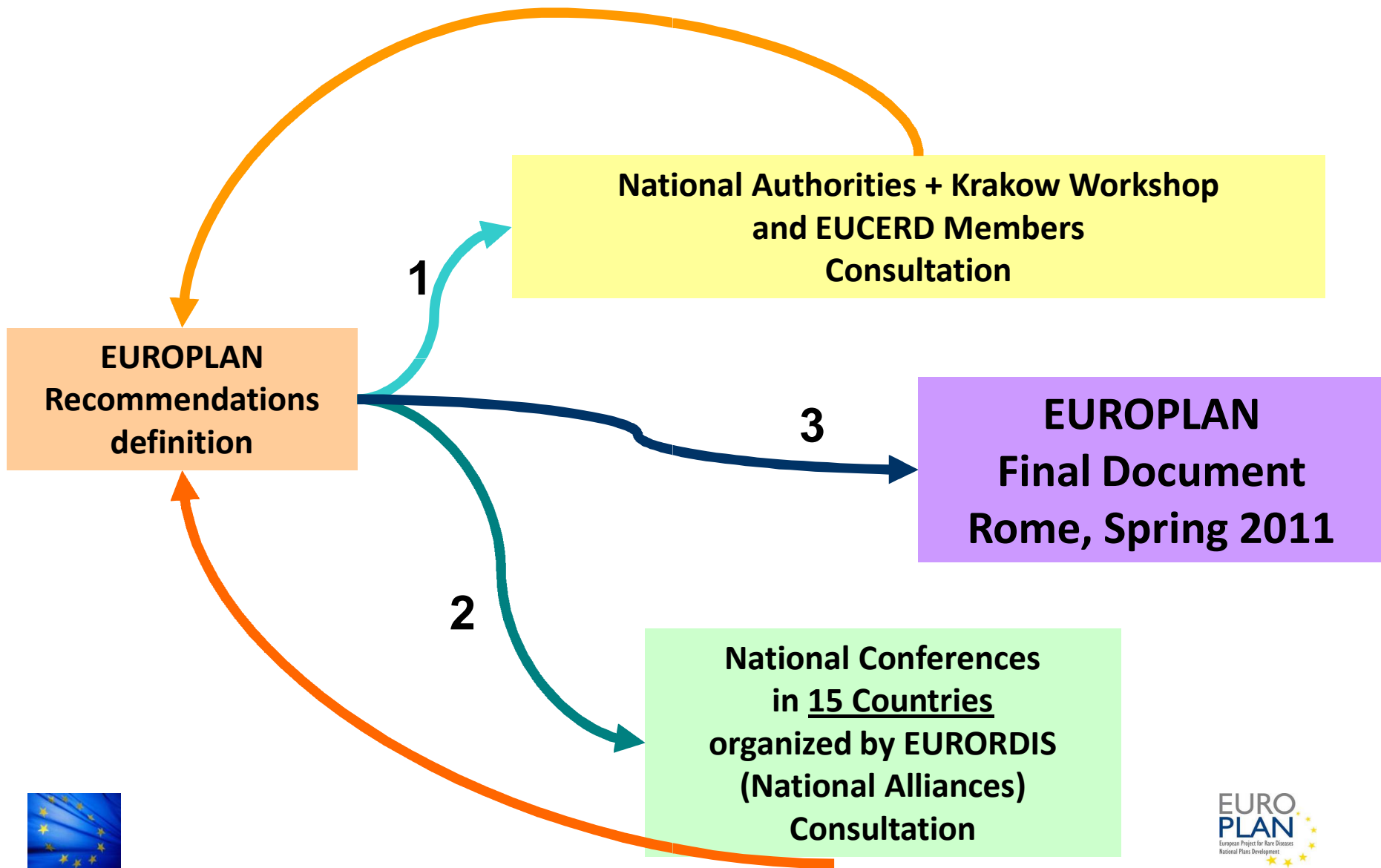
*to be developed and implemented at national level,  
and characterized by identified objectives to be achieved within a  
specified timeframe.*

The allocation of appropriate **resources (human, financial, infrastructural)** and its **monitoring and evaluation** are of special value to ensure the efficacy of the plan or strategy.

## AREAS

- AREA 1. PLANS AND STRATEGIES IN THE FIELD OF RARE DISEASES
- AREA 2. ADEQUATE DEFINITION, CODIFICATION AND INVENTORYING
- AREA 3. RESEARCH ON RARE DISEASES
- AREA 4. CENTRES OF EXPERTISE AND EUROPEAN REFERENCE NETWORKS FOR RARE DISEASES
- AREA 5. GATHERING THE EXPERTISE ON RARE DISEASES AT EUROPEAN LEVEL
- AREA 6. EMPOWERMENT OF PATIENT ORGANISATIONS
- AREA 7. SUSTAINABILITY

# Overview of EUROPLAN consensus process



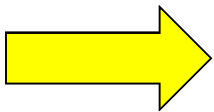
# HERE WE ARE:

- ✓ EUROPLAN Workshop in Krakow (May 13, 2010) with Health Authorities: Europlan recommendations have been approved
- ✓ Discuss the recommendations with stakeholders throughout **National Conferences** organized by EURORDIS (National Alliances) in 15 countries
- ✓ Elaborate the final version of the Document containing the recommendations
- ✓ Present the final version of EUROPLAN documents (recommendations and indicators) during the international conference (Roma, Spring 2011)



# EUROPLAN milestones

- **1 April 2008** – Project starts
- **18 November 2008** – Conference “National Strategies and Plans for Rare Diseases in Europe”, Paris, under the aegis of the EU Presidency (France), EURORDIS and EUROPLAN
- **January- February 2010** – Indicators and EUROPLAN Recommendations have been finalised
- **13 May 2010** – Krakow Workshop with National Authorities to discuss the EUROPLAN Recommendations
- **May 2010 to December 2010** – National Conferences on Rare Diseases organized by EURORDIS- National Alliances in 15 Countries
- **February 2011** – Recommendations finalised
- **April 2011** – Project ends



# European Project for Rare Diseases National Plans Development (EUROPLAN)

## EXPECTED OUTPUTS

- ✓ **To stimulate a discussion and reach a consensus on the importance of national plans / strategies** for structuring all relevant actions in the field of rare diseases
- ✓ **To promote the development of national plans / strategies** for rare diseases within EU MS
- ✓ **To provide instruments and tools** (recommendations, indicators) **to support Countries** in elaborating national plans / strategies for rare diseases



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The European Project for Rare Diseases National Plans Development (EUROPLAN) is a three-year project of the Programme of Community action in the field of Public Health (2003 - 2008), which began in April 2008.

The main goal is to develop recommendations on how to define a strategic plan for rare diseases. The recommendations will provide information on the different steps to develop a strategic plan and, more important, it will include priority areas and actions of intervention in the field of rare diseases.

The project will collect and disseminate information on EU MS national initiatives on rare diseases, on expectations on national plans for rare diseases and on best practices contributing to share experiences, data and effective strategies to address rare diseases.

The National Centre for Rare Diseases (Istituto Superiore di Sanità, Italy) is the leading organization; 30 countries and Eurordis (the European Organisation for rare diseases) participate in the project. This will ensure a broad representation of different EU context and experiences and patients' point of view. In addition, the project will ensure an inclusive and wide engagement of stakeholders - Ministries, regional and local authorities, health care planners, programme managers, health care professionals, researchers and patients

The expected outputs of EUROPLAN are:

- To stimulate a discussion and reach a consensus on the importance of national plans for structuring all relevant actions in the field of rare diseases
- To list priority areas and actions of intervention for addressing rare diseases
- To promote the development of national plans for rare diseases within