

EUROPLAN

European Project for Rare Diseases National Plans Development



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ISS – Rome (Italy)



Goal

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**.

EUROPLAN will develop **recommendations on how to define a strategic plan** for rare diseases. Focusing on the already available MS experiences on RD EUROPLAN will contribute to share information, models and data on effective strategies to address RD.

The Council Recommendation and EUROPLAN

The Commission has proposed a “Council Recommendation on a European action in the field of rare diseases” inviting Member States to define plans or strategies (at the appropriate level) to put in place strategies organised around ideas and approach set out in the Communication.

The recommendations developed by EUROPLAN will provide practical guidance on how this can be done on the basis of existing best practices.

Efficient and effective action for rare diseases depends on a coherent overall strategy based on common approach and integrated into a common European effort.

Specific objectives

- Collect information on EU Member States initiatives on rare diseases
- Identify successful experiences (EUROPLAN will identify the lessons learned ensuring that relevant information will be shared and make available to Member States to facilitate the development of national strategies on RDs taking into account the already available experiences)
- Develop indicators for monitoring the implementation and evaluating the impact of national plans for rare diseases
- Discuss the recommendations and present the Commission Communication on Rare Diseases with local stakeholders
- Disseminate the EUROPLAN Recommendations

Structure of the project

- **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:** Dr. Domenica Taruscio – Director of the National Centre for Rare Diseases (Istituto Superiore di Sanità, Italy)
- The Coordinator is supported by the **Steering Committee (SC)** and the **Advisory Committee (AC)**.

WP overview

- **WP4** will **collect information** on the initiatives undertaken by EU MS on rare diseases.
- **WP5** will **develop indicators** for monitoring the implementation and evaluating the impact of national plans for rare diseases.
- **WP6** will **analyse case studies** to identify **successful experiences**.
- **WP7** will **develop the content of the EUROPLAN recommendations** including methodological guidance on how to develop a national plan.
- **WP8** will **organise national conferences to present the EUROPLAN recommendations**, to discuss the transferability of the recommendations with local stakeholders in different countries and to present the Commission Communication and Council Recommendations on rare diseases.

Partners

EUROPLAN includes

29 Countries and



EURORDIS
Rare Diseases Europe

Eurordis

**EUROPLAN collaborates with the
Office for rare diseases (NIH-USA)**



An inclusive project

- Associated partners

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

- Collaborating partners

Institution	Country
Federal Ministry of Health	Germany
Ministry of Health - Health Care Organisation Department	France
Italian Ministry of Health	Italy
The National Council of Health	Italy
National Organisation for Medicines	Greece
Läkemedelsverket	Sweden
Ospedale S. Giovanni Bosco - Clinical Research Center for RD	Italy
Hospital Dona Estafania	Portugal
Children's University Hospital Zagreb	Croatia
Mater Dei Hospital	Malta
The Cyprus Institute of Neurology & Genetics	Cyprus
University Hospital of Motol	Czech Republic
Department of Medical Biology, Hacettepe University	Turkey
Faculty of Health Sciences, University of Pécs	Hungary
La Sapienza University	Italy
EUROCAT	Italy
Epidemiology Unit - Istituto Nazionale Tumori	Italy
Fundació Doctor Robert	Spain
The Family Federation of Finland	Finland
Office for Rare Diseases, National Institute of Health	USA

National Authorities & health care planners

Health care professionals

Researchers

Patients

Additional Cooperating Partners

- EUROPLAN aims at being an **inclusive project**
- **Additional partners interested in the project are welcome as Additional Cooperating Countries (ACC)**
- **ACCs are formally not part of the grant agreement** however they have **the same rights and duties as Collaborating Partners** thus they can be included in the project website, participate in WP meetings and open workshops but at their own expenses.

Current achievements

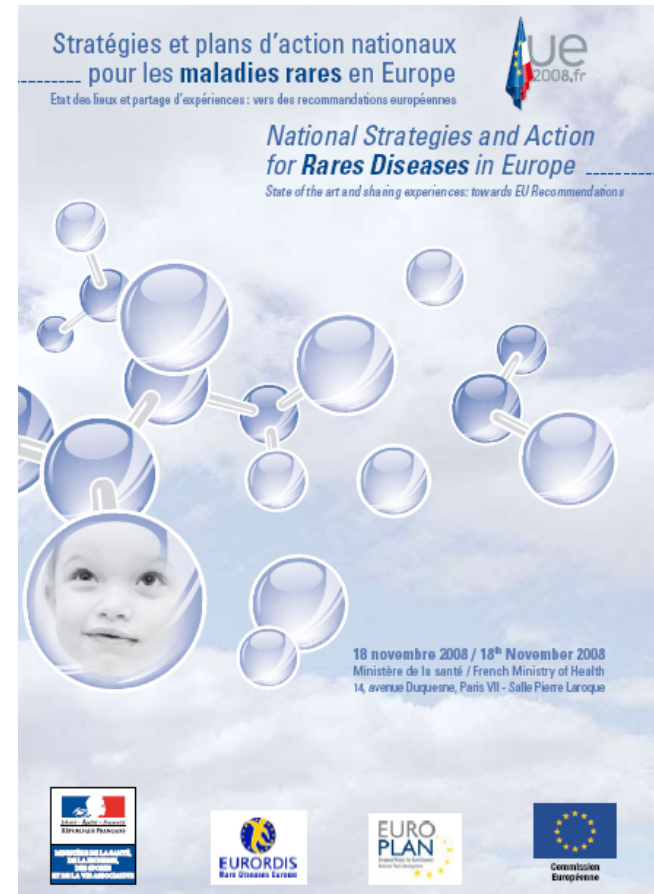
- Project started **April 1°, 2008**
- Kick-off meeting held in Roma (ISS) on **July 7°, 2008**
 - Each work package leader was tasked to give a presentation of his/her WP highlighting potential risks in order to identify together the best way forward for addressing them.
- Questionnaire on opinions and expectations from national plans
- General Meeting with all partners: Paris, **November 17, 2008**
- National Strategies and Plans for Rare Diseases in Europe" "State of the art and sharing experiences: toward EU Recommendations" - **November 18, 2008**
French Ministry of Health
- Next SC meeting February 25-26, 2009 (Rome)

National Strategies and Plans for Rare Diseases in Europe

"State of the art and sharing experiences: toward EU Recommendations"

Under the auspices of:

- EUROPLAN
- French Presidency of the EU
- EURORDIS
- European Commission



Main conclusions

- Rare disease is an area where pool our resources is needed
- There is need to share experiences, objectives, both as regards strategy and resource activation.
- Keys to success:
 - to promote a global approach
 - to support synergies between all stakeholders
 - to identify a national steering for the development of the plans
 - to guarantee the evaluation
 - to cooperate at European level

Summary of the EUROPLAN Conference 'National Strategies & Action for Rare Diseases in Europe' under French Presidency of the Council - December 2008

available on the EU web site

http://ec.europa.eu/health/ph_threats/non_com/rare_diseases_en.htm

Contact us!



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