

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

February 2010

Indicators and EUROPLAN Recommendations finalised

13 May 2010

Krakow Workshop with national authorities to discuss the EUROPLAN Recommendations

May 2010 to December 2010

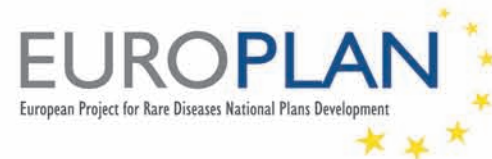
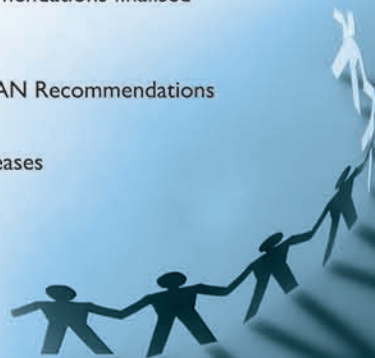
National Conferences on Rare Diseases

February 2011

Recommendations finalised

Spring 2011

Final International Conference in Rome (Italy)



EUROPLAN

European Project for Rare Diseases National Plans Development

NATIONAL CONFERENCES AND ORGANISERS

BULGARIA • Sofia
NAPRD National Alliance of People with RD

CROATIA • Dubrovnik
Hrvatska udruga bolesnikas rijetkim bolestima

DENMARK • Copenhagen
Rare Disorders Denmark

FRANCE • Paris
Alliance Maladies Rares

GERMANY • Berlin
ACHSE All. Chronischer Seltener Erkrankungen

GREECE • Athens
PESPA Greek Alliance for RD

HUNGARY • Budapest
HUFERDIS Rare Disease Hungary

IRELAND • Dublin
GRDO Genetic and Rare Disorders Organisation

ITALY • Rome
UNIAMO Federazione Italiana Malattie Rare

LUXEMBOURG • Luxembourg
Groupe de Travail Maladies Rares

NETHERLANDS • The Hague
VSOP Dutch Genetic Alliance

ROMANIA • Bucarest
RONARD Romanian National Alliance for RD

SPAIN • Burgos
FEDER Federación Española de Enfermedades Raras

SWEDEN • Stockholm
Sällsynta diagnoser

UNITED KINGDOM • Manchester
Genetic Interest Group - Rare Disease UK

For more information:

www.europlanproject.eu

or contact:
europlan@iss.it

Domenica Taruscio
National Centre for Rare Diseases
Istituto Superiore di Sanità
Viale Regina Elena, 299
00161 Roma - Italy
Tel. +39 06 4990 4016

www.iss.it/cnmr



A three-year project co-funded by the European Commission within the framework of the EU program of Community Action in the field of Public Health

EUROPLAN is an operational measure within the European strategy in the field of rare diseases.

Objectives

Develop Recommendations

The EUROPLAN recommendations are a tool to guide step by step efforts to elaborate national plans or strategies for rare diseases and include priority areas and actions of intervention. The aim is to make such initiatives consistent with a common strategy at European level, facilitate the coherence of national initiatives with best practices identified and stimulate the exploitation of possible synergies.

Collect and disseminate best practices

Best practice are collected and disseminated in order to contribute to share experiences, data and effective strategies.

Select indicators

Indicators are selected to monitor the implementation of national plans and strategies and to evaluate their impact. A common set of indicators will also

contribute to ensure the comparability of data among Member States and the implementation status of the Council Recommendation on Rare Diseases in the EU countries.

Support the National Conferences

The National Conferences are events held in 2010 in 16 Member States, organised by national rare disease alliances, where national stakeholders discuss the European strategy, EUROPLAN recommendations and their applicability in their own country. The National Conferences are coordinated by EURORDIS and organised in conjunction with national authorities.

Ultimately, EUROPLAN aims to assist EU Member States in developing national health policies to improve equal access and availability of prevention, diagnosis and treatment for people with rare diseases.



Background

“The Council Recommendation on European Action in the field of Rare Diseases”, adopted by the EU Council in June 2009, recommends Member States to adopt national plans or strategies for rare diseases, before the end of 2013.

EUROPLAN recommendations will provide tools to Member States for developing a plan or strategy, linking with a common framework at the European level.

This “double-level” approach is respectful of national decisions but is expected to ensure a coherent and consistent progress in EU rare diseases care.

Participants

The Italian National Centre for Rare Diseases (Italian National Institute of Health - Istituto Superiore di Sanità) is leading the project.

EUROPLAN involves stakeholders from 31 countries: ministries, authorities, health care planners, programme managers, health care professionals, researchers as well as patients, represented by EURORDIS (European Organisation for Rare Diseases).



PARTNERS

Associated

- 1 - National Centre of Rare Diseases, National Health Institute (Italy) - coordinator
- 2 - Bulgarian Association for Promotion of Education and Science (BAPES) Information Centre for Rare Diseases and Orphan Drugs (Bulgaria)
- 3 - University of Tartu (UT) – Department of Paediatrics (Estonia)
- 4 - Instituto de Salud Carlos III (ISCIII) – Research Institute for Rare Diseases (IIR) (Spain)
- 5 - Canary Foundation of Investigation and Health (FUNCIS) (Spain)
- 6 - Institute of Pharmacological Research Mario Negri (IRFMN) Clinical Research Centre for Rare Diseases (Italy)
- 7 - The Netherlands Organisation for Health Research and Development (ZonMw) Steering Committee on Orphan Drugs (Netherlands)
- 8 - Karolinska Institute (KI) – Department of Woman and Child Health (Sweden)
- 9 - London Strategic Health Authority (NCG) – National Commissioning Group (UK)
- 10 - EURORDIS (European Organisation for Rare Diseases)

Collaborating

- 1 - Human Genetics Centre (Belgium)
- 2 - University Hospital of Motol (Czech Republic)
- 3 - Ministry of Health (Czech Republic)
- 4 - The National Board of Health (Denmark)
- 5 - Federal Ministry of Health (Germany)
- 6 - The St. Joseph, Ballinabearna Ballinhasig, Co. Cork (Ireland)
- 7 - Hellenic Center for Disease Control & Prevention (HCDCP) (Greece)
- 8 - National Organisation for Medicines - Division Pharmaceutical Studies and Research (Greece)
- 9 - The Greek Alliance of Rare Disease (Greece)
- 10 - Autonomous University of Barcelona (Spain)
- 11 - European Network for Rare and Congenital Anaemias (ENERCA) (Spain)
- 12 - Ministry for Health and Social Policy (Spain)
- 13 - The Biomedical Network Research Centre for Rare Diseases (CIBERER) (Spain)
- 14 - Ministry of Health and Sports (France)
- 15 - Health Regional Agency - Friuli Venezia Giulia (Italy)
- 16 - Epidemiology Unit, National Institute for the Study and Care of Tumours (Italy)
- 17 - EUROCAT Tuscany Congenital Anomalies Registry, National Research Council (Italy)
- 18 - Ministry of Health (Italy)
- 19 - “S. Giovanni Bosco” Hospital, Multidisciplinary Centre of Immunopathologic Research (Italy)
- 20 - The Cyprus Institute of Neurology & Genetics - Clinical Genetics Department (Cyprus)

- 21 - Ministry of Health (Latvia)
- 22 - Ministry of Health (Lithuania)
- 23 - Ministry for Health and the Rare Disease Task Force (Luxembourg)
- 24 - University Pécs, Faculty of Health Sciences, Institute of Applied Health Sciences (Hungary)
- 25 - Mater Dei Hospital, Department of Pathology Genetics Unit (Malta)
- 26 - University Children's Hospital (Austria)
- 27 - Ministry of Health (Poland)
- 28 - Polish National Forum on the Treatment of Orphan Diseases – ORPHAN (Poland)
- 29 - Hospital Dona Estafania – Servicio Genética Médica (Portugal)
- 30 - Romanian Prader-Willi Association (Romania)
- 31 - Ministry of Health (Slovenia)
- 32 - University Children's Hospital, Kosice (Slovak Republic)
- 33 - The Family Federation of Finland - Department of Medical Genetics (Finland)
- 34 - Medical Products Agency (Sweden)
- 35 - National Board of Health and Welfare – Health Care and Medical Services Department (Sweden)
- 36 - Children's University Hospital Zagreb (Croatia)
- 37 - Department of Medical Biology, Hacettepe University, Faculty of Medicine, Ihsan Dogramaci Children's Hospital, Sıhhiye (Turkey)
- 38 - Office for Rare Diseases, National Institute of Health (USA)
- 39 - Office of Legislative and Regulatory Modernisation Policy, Planning and International Affairs Directorate Health Products and Flood Branch (Canada)