

08.30	<i>Registration of participants</i>
09.15	<i>Welcome to participants</i> Enrico Garaci Session I Chairpersons: Helena Kääriäinen, Filippo Palumbo
09.40	<i>The European Commission Actions on Public Health</i> Antoni Montserrat
10.00	<i>The European Commission Actions on Research</i> Catherine Berens
10.20	<i>The EUROPLAN project: objectives and results</i> Domenica Taruscio
10.45	<i>Coffe Break</i>
11.00	<i>EUROPLAN Recommendations</i> Jolanda Huizer
11.15	<i>EUROPLAN Indicators</i> Manuel Hens Péres, Manuel Posada de la Paz
11.30	Round Table I “ <i>The National EUROPLAN Conferences: main results and key questions for discussion</i> ” Chairpersons: Yann Le Cam, Antoni Montserrat Radka Tincheva, Vladimir Tomov (Bulgaria) Ivo Baric (Croatia) Marianne Jespersen (Denmark) Alain Garcia (France) Mirjam Mann (Germany) Despina Sotiri, Gerassimos Voutsinas (Greece) János Sándor (Hungary) John Devlin, Avril Daly (Ireland) Bruno Dallapiccola, Renza Barbon Galluppi (Italy) Jakub Adamski (Poland) Dorica Dan (Romania) Conception Colomer Revuelta, Claudia Delgado (Spain) Britta Berglund (Sweden) Harry Seeverens (The Netherlands) Edmund Jessop (United Kingdom) EURORDIS EUROPLAN Advisors: Simona Bellagambi, Britta Berglund, Avril Daly, Dorica Dan, Mirjam Mann

13.15	<i>Lunch</i>
14.00	Round Table II “ <i>Update on Eastern European Countries</i> ” Chairpersons: Paola Facchin, Rumen Stefanov Albert Matevosyan (Armenia) Panayiotis Voskos (Cyprus) Oleg Kvlividze (Georgia) Svetlana Karimova (Russia) Meral Ozguc (Turkey) Session II Chairpersons: Helmut Hintner, Arrigo Schieppati
15.00	<i>EUROPLAN: Lessons learned</i> Edmund Jessop
15.15	<i>Orphan drugs: accessibility and sustainability</i> Kerstin Westermark
15.30	<i>Strengthen the collaboration between EUROPLAN and E-Rare</i> Sophie Koutouzov
15.45	<i>Strengthen the collaboration between EUROPLAN and EUROCAT</i> Fabrizio Bianchi
16.00	<i>EUROPLAN: next steps through the European Commission Joint Action on Rare Diseases</i> Domenica Taruscio
16.15	<i>Activities of the European Committee of Experts on Rare Diseases (EU CERD)</i> Ségolène Aymé
16.30	<i>Discussion</i>
17.00	<i>Conclusions</i> Antoni Montserrat

Jakub Adamski - Drug Policy and Pharmacy Department , Ministry of Health - EU CERD Member - Poland
Ségolène Aymé - Chair of European Committee of Experts on Rare Diseases (EU CERD), Orphanet - France
Renza Barbon Galluppi - Uniamo F.I.M.R. Onlus - Italy
Ivo Baric - Division for Metabolic Diseases, University Hospital Center - EU CERD Member - Croatia
Simona Bellagambi - Uniamo F.I.M.R. Onlus - EURORDIS EUROPLAN Advisor - Italy
Catherine Berens - Medical and Public Health Research Unit, DG Research - EU
Britta Berglund - Department of Surgical Gastroenterology, Karolinska University Hospital - EURORDIS EUROPLAN Advisor - Sweden
Fabrizio Bianchi - EUROCAT Tuscany Congenital Anomalies Registry, National Research Council - EUROPLAN Collaborating Partner - Italy
Oleg Kvlividze - Georgian Foundation for Genetic and Rare Diseases - EUROPLAN Additional Collaborating Partner - Georgia
Conception Colomer Revuelta - Ministry of Health - EUROPLAN Advisory Board - EU CERD Member - Spain
Bruno Dallapiccola - Paediatric Hospital "Bambino Gesù" - EU CERD Member - Italy
Avril Daly - Genetic and Rare Disorders Organisation - EURORDIS EUROPLAN Advisor - Ireland
Claudia Delgado - Spanish Federation for Rare Diseases - Spain
Dorica Dan - Romanian Prader Willi Association - EURORDIS EUROPLAN Advisor - Romania
John Devlin - Department of Health and Children, Ministry of Health - EU CERD Member - Ireland
Paola Facchin - Coordination Center for Rare Diseases, Veneto Region - Italy
Enrico Garaci - President of the Istituto Superiore di Sanità - Italy
Alain Garcia - Inspection Générale des Affaires Sociales - France
Manuel Hens Péres - Institute of Rare Diseases Research - Instituto de Salud Carlos III - Ministry of Science and Innovation - EUROPLAN Associated Partner - Spain
Helmut Hintner - Department of Dermatology, Paracelsus Medical University Salzburg - EU CERD Member - Austria
Jolanda Huizer - The Netherlands Organisation for Health Research and Development (ZonMw) - Steering Committee on Orphan Drugs - EUROPLAN Associated Partner - The Netherlands
Marianne Jespersen - The National Board of Health - EU CERD Member - Denmark
Edmund Jessop - London Strategic Health Authority -National Commissioning Group - EUROPLAN Associated Partner - EU CERD Member - UK

SPEAKERS AND CHAIRPERSONS

Helena Kääriäinen - National Institute for Health and Welfare - EU CERD Vice Chair - Finland

Svetlana Karimova - Russian Association of Organizations of Patients with Rare Diseases «Genetics» - EUROPLAN Additional Collaborating Partner - Russia

Sophie Koutouzov - GIS - Institut des Maladies Rares (INSERM/GIS) - E-RARE Coordinator - France

Oleg Kvlividze - Georgian Foundation for Genetic and Rare Diseases - EUROPLAN Additional Collaborating Partner - Georgia

Yann Le Cam – European Organisation for Rare Diseases (EURORDIS) - EUROPLAN Associated Partner - EU CERD Vice Chair

Mirjam Mann German Alliance for Rare Diseases - EURORDIS EUROPLAN Advisor - Germany

Albert Matevosyan - Department of Medical Genetics of Yerevan State Medical University, "Neurohereditary Diseases" Charity Association - EUROPLAN Additional Collaborating Partner - Armenia

Antoni Monserrat - Policy Officer for Rare and Neurodevelopmental Diseases Health and Consumers General-Directorate (SANCO) - EC

Meral Ozguc - Department of Medical Biology, Hacettepe University, Faculty of Medicine, Ihsan Dogramaci Children's Hospital - EUROPLAN Collaborating Partner - Turkey

Filippo Palumbo - Head of the Department of Quality, Ministry of Health - Italy

Manuel Posada de la Paz - Institute of Rare Diseases Research - Instituto de Salud Carlos III - Ministry of Science and Innovation - EUROPLAN Associated Partner - Spain

János Sándor - Pécs University, Institute of Applied Health Sciences Department of Public Health - EU CERD Member - Hungary

Arrigo Schieppati - Institute of Pharmacological Research "Mario Negri", Clinical Research Centre for Rare Diseases - EUROPLAN Associated Partner - Italy

Harry Seeverens - Ministry of Health Welfare and Sport - EU CERD Member - The Netherlands

Despina Sotiri - Hellenic Center for Disease Control & Prevention - EU CERD Member - Greece

Rumen Stefanov - Bulgarian Association for Promotion of Education and Science - EUROPLAN Associated Partner - Bulgaria

Radka Tincheva - Department of Clinical Genetics University Pediatric Hospital - EU CERD Member - Bulgaria

Domenica Taruscio - National Centre for Rare Diseases, Istituto Superiore di Sanità - EUROPLAN Coordinator - EU CERD Member - Italy

Vladimir Tomov - Bulgarian National Patient Alliance - Bulgaria

Gerassimos Voutsinas - Greek Alliance for Rare Diseases - Greece

Panayiotis Voskos - Cyprus Alliance for Rare Disorders - Cyprus

Kerstin Westermark - Committee for Orphan Medicinal Products (COMP), European Medicines Agency (EMA)

GENERAL INFORMATION

EUROPLAN is a three-year project co-funded by the European Commission, it is an operational measure within the European strategy in the field of rare diseases.

EUROPLAN is coordinated by the Italian National Centre for Rare Diseases (Istituto Superiore di Sanità) and involves 34 Countries and EURORDIS.

For more information: www.europlanproject.eu

Venue

Aula Pocchiari, Istituto Superiore di Sanità
Viale Regina Elena, 299 – Rome - Italy

Participation

The participation is free, but registration is required for all participants through the website of Europlan Project (<http://www.europlanproject.eu>).

Translation English/Italian and Italian/English will be available.

Travel and accommodation are at participant's expenses.

The Certificate of attendance will be given at the end of the Conference.

Scientific Director

Domenica Taruscio

Scientific Secretariat:

Fabio Candura, Giorgio Vincenti

Technical Secretariat:

Stefano Diemoz, Donata Izzo,
Alessandro Pinter, Stefania Razeto

*National Centre for Rare Diseases
Istituto Superiore di Sanità
Viale Regina Elena, 299 - 00161 Roma*

Tel. 06.4990.4017

Fax. 06.4990.4370

Web site: www.iss.it/cnrm

www.europlanproject.eu

E-mail: europlan@iss.it



FINAL CONFERENCE

Rome, 25 February 2011

*Aula Pocchiari
Istituto Superiore di Sanità
Via Regina Elena, 299 – 00161 Rome, Italy*