

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>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, Christel Nourissier (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, Annika Larsson (Sweden) Harry Seeverens (The Netherlands) Edmund Jessop (United Kingdom)

EURORDIS EUROPLAN Advisors: **Simona Bellagambi, Britta Berglund, Avril Daly, Dorica Dan, Mirjam Mann, Christel Nourissier**

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 Koutouзов
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> <i>Discussant: Milan Macek</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

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

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

SPEAKERS AND CHAIRPERSONS

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

Sophie Koutouzov - Institut des Maladies Rares (INSERM) - 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

Milan Macek – Institute of Biology and Medical Genetics, Charles University - EU CERD Member – Czech Republic

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 Montserrat - Policy Officer for Rare Diseases, Neurodevelopmental Disorders and the European Health Examination Survey, Health and Consumers General-Directorate (SANCO), Directorate C “Public Health and Risk Assessment” - EC

Christel Nourissier - European Organisation for Rare Diseases (EURORDIS) - EURORDIS EUROPLAN Advisor - France

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

SPEAKERS AND CHAIRPERSONS

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

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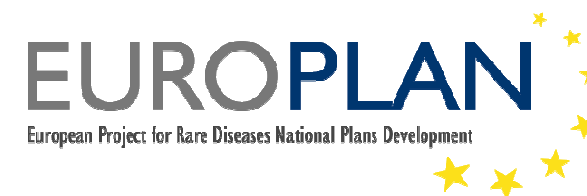
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FINAL CONFERENCE

Rome, 25 February 2011

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