

## International Conference "Rare Diseases: Europe's Challenges"

Camera dei Deputati  
Aula dei Gruppi Parlamentari  
Campo Marzio, 74 - Roma

Organized by

The National Centre for Rare Diseases  
Italian National Institute of Health (ISS)  
Interparliamentary Group on Rare Diseases

**October 31, 2014**

*10.00 - 11.00 Welcome Address*

President of the Chamber of Deputies

**Laura Boldrini**

Minister of Health

**Beatrice Lorenzin**

Commissioner of the Italian National Institute of Health

**Walter Ricciardi**

General Director of the Italian Medicines Agency

**Luca Pani**

President of the Pontifical Council for Health Pastoral Care

**Msgr. Zygmunt Zimowski**

### *Session 1*

*Chairs:* **On. Paola Binetti** - Member of the Italian Chamber of Deputies, **Bruno Dallapiccola** - Scientific Director of Bambino Gesù Hospital

*11.00 - Rare Diseases: Europe's challenges*

**Paola Testori Coggi** - Paola Testori Coggi - Director General of the Directorate - General for Health and Consumers

*11.15 - European Reference Networks*

**Michael Huebel** - Head of Unit, Health Programme and Diseases, DG SANCO, European Commission

*11.30 - Global initiatives to foster research in rare diseases: from prevention to treatment*

**Paul Lasko** - Chair of International Rare Diseases Research Consortium

*11.45 - EUROPLAN: from the Council Recommendations to National Plans to actions*

**Domenica Taruscio** - Director of National Centre for Rare Diseases, Italian National Institute of Health

*12.00 - The Italian National Network for Rare Diseases*

**Maria Elena Congiu** - Ministry of Health

*12.15 - Centres of expertise and Regional Networks*

**Paola Facchin** - Coordinator of the Interregional Committee on Rare Diseases

*12.30 - A community for rare diseases: an experience of participatory quality assessment*

**Giovanni Caracci, Micaela Cirilli** - AGENAS

*12.45 - 13.15 Discussion*

*13.15 - 14.15 Break*

### *Session 2*

*Chairs:* **Mirella Taranto** - Head of Press Office, Italian National Institute of Health, **Domenica Taruscio** - Director of National Centre for Rare Diseases, Italian National Institute of Health

*14.15 - Patients and families: unmet needs*

*Participants:* **Renza Barbon Galluppi** - President of UNIAMO FIMR Onlus, **Yann Le Cam** - Chief Executive Officer, EURORDIS, **Msgr. Andrea Manto** - Director of the Centre for Health Pastoral Care

*15.00 - Rare patients, frequent stories: narrative and evidence based medicine*

**Amalia Egle Gentile** - National Centre for Rare Diseases, Italian National Institute of Health

*15.15 - Towards a culture of data sharing and best practices*

**Luciano Vittozzi** - National Centre for Rare Diseases, Italian National Institute of Health

*15.30 Discussion*

*16.00 - Towards new treatments: research, development, access and rehabilitation*

*Research*

**Giuseppe Novelli** - Rector of Tor Vergata University, Rome

*New frontiers in genetic definition and care of Rare Diseases*

**Alessandra Ferlini** - Director of the Medical Genetics Unit, University of Ferrara

*Development of orphan drugs*

**Massimo Scaccabarozzi** - President of Farminindustria

*Treatments and rehabilitation*

**Eugenio Mercuri** - Director of Dept. of Paediatric Neurology, Catholic University, Rome

*16.45 General discussion*

*17.15 Conclusions*



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On-line registration:

<https://www.surveymonkey.com/s/SWVSQVD>