



2014  
Presidenza Italiana del Consiglio  
dell'Unione Europea



Organized by

Interparliamentary Group  
on Rare Diseases

# International Conference Rare Diseases Europe's Challenges

Roma, 31 ottobre 2014

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

## Schedule

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  
Paola Binetti Member of the Italian Chamber of Deputies  
Bruno Dallapiccola Scientific Director of Bambino Gesù Hospital

11.00 *EU Action on Rare Diseases*  
Michael Huebel

Head of Unit, Health Programme and Diseases, DG SANCO, European Commission

11.20 *Global initiatives to foster research in rare diseases:  
from prevention to treatment*  
Paul Lasko

Chair of International Rare Diseases Research Consortium

11.40 *EUROPLAN: from the Council Recommendations  
to National Plans to Actions*  
Domenica Taruscio

Director of the 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

12.20 *Centres of expertise and Regional Networks*  
Paola Facchin

Coordinator of the Interregional Committee on Rare Diseases

12.40 *A community for rare diseases: an experience  
of participatory quality assessment*  
Giovanni Caracci, Micaela Cirilli  
AGENAS

13.00 - 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 the 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 Vitozzi

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 the Child Neuropsychiatry Unit, Catholic University, Rome

17.00 General discussion

17.30 Conclusions

Under the patronage



Senato  
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Camera dei Deputati



Ministero della Salute



VICARIATO DI ROMA  
Centro per la Pastorale Sanitaria



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