International Conference
Rare Diseases Europe’s Challenges
Roma, 31 ottobre 2014
Camera dei Deputati
Aula dei Gruppi Parlamentari
Campano 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
Bruno Dallapiccola

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
Domenica Taruscio

14.15  Patients and families: unmet needs
Participants
Renza Barbon Galluppi
Yann Le Cam
Msgr. Andrea Manto

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 Vittolzi
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 Farmindustria

Treatments and rehabilitation
Eugenio Mercuri
Director of the Child Neuropsychiatry Unit, Catholic University, Rome

17.00  General discussion

17.30 Conclusions

Under the patronage

Partners

Organized by

Interparliamentary Group on Rare Diseases

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