Organized by



CNMR

Interparliamentary Group on Rare Diseases

International Conference are Diseases Europe's Challen

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 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 Yann Le Cam President of UNIAMO FIMR Onlus 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

Towards a culture of data sharing and best practices 1515 Lucianó 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 Farminidustria

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

17.00 General discussion

17.30 Conclusions





VICARIATO DI ROMA Centro per la Pastorale Sanitaria

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

2014

Presidenza Italiana del Consiglio

dell'Unione Europea

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

The Italian National Network for Rare Diseases Maria Elena Congiu 12.00 Ministry of Health

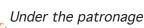
Centres of expertise and Regional Networks Paola Facchin 12.20

Coordinator of the Interregional Committee on Rare Diseases

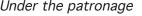
A community for rare diseases; an experience 12.40 of participatory quality assessment Giovanni Caracci, Micaela Cirilli AGENAS

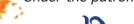
13.00 - 13.15 Discussion

13.15 - 14.15 Break











Camera dei Deputati della Repubblica

Senato