

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>