



Rare Diseases Registries Workshop

Hospital Universitario La Paz, Madrid, Spain

21-22 March 2017

PROGRAMME

Day 1

13:00-13:20 Welcome and introduction
DG SANTE, CHAFEA, Spanish Ministry of Health, Social Services and Equality, H. La Paz-CIBERER and Instituto de Salud Carlos III

13:20-13:40 Overview of Health Policies on Rare Diseases

Speaker
Gerhard Steffes – DG SANTE

13:40-14:00 Overview of EU Health Programme projects funded between 2008-2015 related to Rare Diseases registries

Speaker
Hristina Mileva – Chafea

Session 1: Towards an European platform on Rare Diseases Registration

Chair: *TBD, DG-SANTE*

14:00-14:20 European Platform on Rare Diseases Registration

Speaker
Agnieszka Kinsner-Ovaskainen – DG Joint Research Centre
Directorate F - Health, Consumer and Reference Materials, Health in Society Unit (JRC F1), Italy.

14:20-14:40 EUROCAT - European Surveillance of Congenital Anomalies

Speaker
Amanda Julie Neville, University of Ferrara.
President of EUROCAT Association and leader of EUROCAT Registry, Italy

14:40-15:00 SCPE - Surveillance of Cerebral Palsy in Europe

Speaker

*Catherine Arnaud, Toulouse III University
Chair SCPE, France*

15:00-15:20 EUCERD Core Recommendations on RD patient registration and data collection

Speaker

*Victoria Hedley, Newcastle University
RD-ACTION Thematic Coordinator, UK*

15:20-16:00 Plenary Discussion: Interoperability of RD Registries

16:00-16:30 Coffee break

Session 2: Main results of the European Union's Health Programme – Rare Diseases Registries related projects

Chair: *Eva Bermejo, Instituto de Investigación en Enfermedades Raras –Instituto de Salud Carlos III*

16:30-16:50 EPIRARE - European Platform for Rare Disease Registries

Speaker

*Luciano Vittozzi. National Centre for Rare Diseases, National Institute for Health.
Coordinator of EPIRARE, Italy*

16:50-17:10 PARENT Joint Action - Cross Border Patient Registries iNiTiative

Speaker

*Marija Magajne, Nacionalni Inštitut za Javno Zdr.
Coordinator of the PARENT JA, Slovenia*

17:10-17:30 RD-ACTION (Rare Diseases Joint Action)

Speaker

*Victoria Hedley, Newcastle University
RD-ACTION Thematic Coordinator, UK*

17:30-17:50 Sharing experience with the European Union's Research and Innovation Programme Projects – RD-CONNECT (An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for RD research)

Speaker

*Elizabeth Wood, Project manager of RD-Connect.
Newcastle University UK*

17:50-18:30 Plenary Discussion: Best practices in the field of RD Registries

19: 30 Reception cocktail / dinner

Day 2

Session 3: Example of successful EU funded registries

Chair: *Susan Webb, Scientific Assistant Director of CIBERER and coordinator of ERCUSYN, Spain*

9:30-9:45 E-HOD - European registry and network for homocystinurias and methylation defects

Speaker

*M^a Luz Couce Pico, Complejo Hospitalario Universitario de Santiago – CIBERER.
E-HOD, Spain*

9:45-10:00 E-IMD - European registry and network for Intoxication type Metabolic Diseases

Speaker

*Angels García-Cazorla, Hospital Sant Joan de Déu – CIBERER.
E-IMD, Spain*

10:00-10:10 Q & A

Session 4: Challenges encountered by RD patient registries

Chair: *Pablo Lapunzina, Scientific Director of CIBERER, Spain*

10:10-10:30 Challenge 1: Integration and interoperability of EU and national RD registries

Speaker

*Manuel Posada de la Paz, Instituto de Investigación en Enfermedades Raras – Instituto de Salud Carlos III
Spanish Rare Diseases Registry coordinator, Spain*

10:10-10:30 Challenge 2: EMA Initiative on Patients Registries

10:50-11:20 Coffee break

11:20-11:40 Challenge 3: Public-Private Partnership for Rare Diseases Registries

11:40-12:00 Challenge 4: Registries and patient involvement: Patient-Powered Patient Registries

Speaker

*Virginie Bros-Facer, Research Infrastructure Project Manager
Eurordis, France*

12:00-12:20 Challenge 5: Registries through the European Reference Networks

Speaker

TBD DG-SANTE

12:20-13:00 Plenary Discussion: Current and future situation of patient registries

13:00-13:15 Closing remarks

Hristina Mileva – Chafea

Susan Webb - CIBERER

13:15 Lunch
