

Rare Diseases Registries Workshop

Madrid, 21st - 22nd March 2017

Preliminary Program

Day 1: 21st March 2017

- 13:00-13:20 Welcome and introduction (*CHAFEA, DG-SANTE; Spanish Ministry of Health, Social Services and Equality and Instituto de Salud Carlos III*)
- 13:20-13:40 Overview of Health Policies on Rare Diseases (*DG SANTE*)
- 13:40-14:00 Overview of EU Health Programme projects funded between 2008-2015 related to Rare Diseases registries (*CHAFEA*)

Session 1: Towards an European platform on Rare Diseases Registration

Chair: DG SANTE

- 14:00-14:20 European Platform on Rare Diseases Registration
- 14:20-14:40 EUROCAT - European Surveillance of Congenital Anomalies
- 14:40-15:00 SCPE - Surveillance of Cerebral Palsy in Europe
- 15:00-15:20 EUCERD Core Recommendations on RD patient registration and data collection
- 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: Instituto de Salud Carlos III representative

- 16:30-16:50 EPIRARE - European Platform for Rare Disease Registries
- 16:50-17:10 PARENT Joint Action - Cross Border Patient Registries iNITiative
- 17:10-17:30 RD-ACTION (Rare Diseases Joint Action)

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).

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

19: 30 *Reception cocktail / dinner*

Day 2: 22nd March 2017

Session 3: Example of successful EU funded registries

Chair: CIBERER representative

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

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

10:00-10:10 Q & A

Session 4: Challenges encountered by RD patient registries

Chair: CIBERER representative

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

10:30-10:50 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 (PPRs)

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

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

13:00-13:15 Closing remarks

13:15 *Lunch*