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EUCERD Joint Action Final Conference: 'Working for Rare Diseases'

15th September 2015

Hotel Parc Belle-Vue, 5 Avenue Marie-Therese L-2132 LUXEMBOURG

Aim of the Conference: To showcase the achievements of the EJA 2012-2015 and analyse the current state of the art of rare disease (RD) activity across the European Union, by exploring progress and remaining challenges in key areas of RD healthcare, social care and research, and strengthening collaborations with stakeholder groups and relevant initiatives. The conference is intended to facilitate a seamless transition between the EUCERD Joint Action and RD-Action.

Agenda

09:00 Welcome by Kate Bushby as EJA Coordinator, Domenica Taruscio, and the European Commission

Session 1: Resource-Building of the EUCERD Joint Action

09:10–09:20 Achievements of the EUCERD Joint Action (K. Bushby)

09:20-11:00 Presentations of Resources and Recommendations supported by the EJA:

- Quality of care in Centres of Expertise (Francesc Palau)
- RD European Reference Networks (Kate Bushby)
- Specialised social services (Dorica Dan)
- Cross-border genetic testing (Helena Kääriäinen)
- Codification of Rare Diseases (Ségolène Aymé)

11:00-11:20 Coffee Break

Session 2: RD Research, Therapeutics and Translation into the health sphere

11:20-11:40 Resources of RARE-Bestpractices (Cristina Morciano and Domenica Taruscio)

11:40-12:00 BURQOL-RD: An instrument to assess the impact of new health policies, interventions and treatments in the field of RD (Renata Linertová)

12:00-12:20 E-RARE: Support for transnational research and integration (Daria Julkowska)

12:20-12:40 IRDiRC policies and impact on the national level (Ségolène Aymé)

12:40-13:15 Discussion and Questions (*Chaired by D. Taruscio and K. Bushby*)

13:15-14:15: Lunch (provided)

Session 3: Rare Disease Registries – Integrating Initiatives

14:15-14:45 Resources from EPIRARE and the Registry Tasks of RD-Connect (Domenica Taruscio and Manuel Posada)

14:45-15:15 EJA Resources for RD Registration: Recommendations, Minimum Data-set, Thesaurus of Terminology (Thomas Wagner)

15:15-15:35 Key outputs of PARENT JA (Borna Plese)

15:35-16:00 EU Platform for RD Registration - progress and next steps (Ciarán Nicholl)

16:00-16:30 Discussion and Questions (*Chaired by K. Bushby*)

16:30-17:00 Coffee Break

Session 4: National Plans and Strategies for RD – supporting the implementation of national activities

17:00-17:30 EUCERD Recommendations on Indicators for National Plans/Strategies for RD and Capacity-building (Rita Ferrelli and Domenica Taruscio)

17:30-18:00 Achievements of EUROPLAN National Conferences and Next Steps (Valentina Bottarelli)

18:00-18:15 Discussion and Questions (*Chaired by Y. le Cam*)

18:15-18:30 From the EUCERD Joint Action to RD-Action Policy & Integration: Next steps and priorities (Kate Bushby)

18:30 Conference Ends

