

**RDI Launch Event
May 28, 2015
Hotel Rafael Atocha, Madrid**

Agenda

14.30 - 14.40: Opening Speech – *Yann Le Cam, Chief Executive Officer, EURORDIS*

14.40 - 15.10: RDI Presentation – *Paloma Tejada, Senior Manager Rare Diseases International, EURORDIS*

Speaking with one voice

15.10 - 15.30: Presentation of the Joint Declaration “Rare Diseases as an International Public Health Priority” - *Flaminia Macchia, Public Affairs Director, EURORDIS*

15.30 - 15.40: Q&A

15.40 -16.05 Group Photo & Coffee Break

Panel I: Influencing the global health agenda

Moderator: *Kevin Rufang Huang, President, Chinese Organisation for Rare Diseases*

16.10 – 16.20: Introducing Rare Diseases in the UN system: Working with the International Alliance of Patients’ Organizations, *Durhane Wong-Rieger, Immediate Past Chair, IAPO*

16.20 - 16.30: Advocating the WHO: A case study from the International Patient Organization for Primary Immunodeficiencies, *Johan Prevot, Executive Director, IPOPI*

16.30 - 16.40: Making rare diseases visible on the UN agenda: Forming a Committee on Rare Diseases at the Conference of NGOs in Consultative Relationship with the United Nations – ECOSOC, *Anders Olauson, Chair, AGRENSKA Sweden (remotely)*

16.40 - 16.50 Discussion

Panel II: Collaboration and partnerships

Moderator: *Pamela Gavin, Chief Operating Officer, National Organization for Rare Disorders (NORD)*

16.50 - 17.00: Fostering patient involvement in international research: Getting more patient representation at the International Rare Diseases Research Consortium (IRDIRC) Executive Committee, *Sharon Terry, President and Chief Executive Officer, Genetic Alliance US (remotely)*

17.00 - 17.10: The role of industry in global advocacy. Dialogue with the International Federation of Pharmaceutical Manufacturers (IFPMA), *Vanessa Peberdy, Global Health, IFPMA*

17.10 - 17.20: Defining relations between RDI and the International Conference for Rare Diseases and Orphan Drugs (ICORD), *Manuel Posada, President-Elect of ICORD*

17.20 - 17.35: Discussion

17.35 - 17.45: Adoption of the Joint Declaration

17.45 - 17.55: Organisation of elections of the Council of RDI

17.55 - 18.00: Take home message

Cocktail