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