RDI Global Online Meeting

May 19, 2020

14.00 – 18.00 CET

14.00 – 14.10 Welcoming remarks

Leveraging Universal Health Coverage to advance rare disease policy

14.10 – 14.25 Celebrating the inclusion of rare diseases in landmark United Nations Political Declaration on UHC

Durhane Wong-Rieger, RDI Chair and President & CEO Canadian Organization for Rare Disorders

14.25 – 14.35 Rare Diseases and the COVID 19 crisis: a regional response from the patient community

Jesus Navarro, Vice President, Iberoamerican Alliance for Rare Diseases (ALIBER) and President, Mexican Organisation for Rare Diseases (OMER) tbc

14.35 – 14.45 Advocating for the integration of rare diseases in national policies within the framework of UHC – the case of Spain

Alba Ancochea, CEO, Federación Española de Enfermedades Raras

14.45 – 15.00 Q&A

Global collaborations to achieve Universal Health Coverage

15.00 – 15.10 Memorandum of Understanding between RDI and the World Health Organization

Yann Le Cam, Member of the Council of RDI and CEO EURORDIS – Rare Diseases Europe

15.10 – 15.15 The vision of global networks of centres of excellence for rare diseases

Dr Rüdiger Krech, Director, Universal Health Coverage and Health Systems, WHO (Video presentation made at Rare 2030 Panel of Experts Meeting, 7 November, 2019)

15.15 – 15.30 Towards a WHO Collaborative Global Network for Rare Diseases: Needs Assessment and Concept development

Matt Bolz-Johnson, RDI Health care and CGN4RD Advisor

15.30 – 15.45 Towards an international framework of operational description of rare diseases and key prevalence and incidence figures

Ana Rath, Director, Orphanet International

15.45 – 16.00 Q&A

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Working with WHO to improve access to rare disease medicinal products:

Yann Le Cam, Member of the Council of RDI and CEO EURORDIS – Rare Diseases Europe

16.20- 16.35 Case study of a patient group that has a diagnostic included in a WHO Priority List

Johan Prévot, Executive Director, IPOPI - International Patient Organisation for Primary Immunodeficiencies

16.35 – 17.00 Q&A

COVID-19 Global Health Crisis: Responses from the rare disease patient community

17.00 – 17.40 Panel discussion and open session for all participants

Panellists:

• Durhane Wong-Rieger, President & CEO, Canadian Organization for Rare Disorders
• Jesus Navarro, Vice President, Iberoamerican Alliance for Rare Diseases
• Kelly du Plessis, CEO and Patient Advocacy, Rare Diseases South Africa
• Lisa Sarfaty, Director of Strategic Planning and Project Development, National Organization for Rare Disorders (NORD), USA
• Samuel Agyei Wiafe, Executive Director, Rare Disease Ghana Initiative
• Sandra Courbier, Chief Executive Officer of EURORDIS – Rare Diseases Europe

17.40 – 18.00 Q&A