



RARE  
DISEASES  
INTERNATIONAL

## **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:**

16.10 – 16.20 WHO Essential Medicines List and WHO Essential in Vitro Diagnostics List: Why, What & How

*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