

## ON THE ROAD TOWARDS COVID-19 RECOVERY & DELIVERY OF THE SDGS:

# ADDRESSING THE CHALLENGES OF PERSONS LIVING WITH A RARE DISEASE AS A HUMAN RIGHTS, SUSTAINABLE DEVELOPMENT AND EQUITY PRIORITY

7 July 2021. 8.00 – 09.30 EDT /14.00 – 15.30 CET



Moderator Ms. Durhane Wong-Rieger, Chair, Rare Diseases International (RDI)

### 8.00 – 8.15 Welcoming Remarks (pre-recorded videos)

- Her Majesty Queen Letizia of Spain
- Her Excellency Michelle Bolsonaro, First Lady of Brazil and Her Excellency Damara Alves, Minister for Women, Family and Human Rights of Brazil

### 8.15 – 8.20 Keynote Address

- Mr. Craig Mokhiber, Director of the New York Office, OHCHR

### 8.20 – 8.35 Video - 'Dear UN'

Testimonies from the global rare disease community linked to the SDGs

### 8.35 – 9.10 Multi-stakeholder panel discussion

The value of UN action to address the challenges of persons living with a rare disease and move towards inclusive sustainable development.

- Rev. Dr. Liberato C. Bautista, President of CoNGO (Conference of NGOs in Consultative Relationship with the United Nations)
- Ms. Maria Montefusco, Chairperson of Rare Diseases Sweden and member of the Board of EURORDIS
- Dr. Lucia Monaco, Chair of the International Rare Diseases Research Consortium (IRDiRC)
- Dr. Gareth Baynam, Director of Western Australia's Undiagnosed Diseases Program

### 9.10 – 9.25 Q&A from the Audience

### 9.25 – 9.30 Closing Remarks

- Mr. Anders Olauson, Chair, NGO Committee for Rare Diseases