

# NETWORKING EXPERTS, CENTERS OF EXPERTISE AND PATIENT ORGANIZATIONS TO STRENGTHEN HEALTH SYSTEMS FOR RARE DISEASES

24 May 2022 | 18:30 to 20:30 (CET)



RARE  
DISEASES  
INTERNATIONAL



## Opening & Keynote

18:30-18:40	• Opening Remarks	<b>Ms. Durhane Wong-Rieger</b> , Council Chair RDI
18:40-18:50	• Keynote Address	<b>Dr. Rüdiger Krech</b> , Director, Health Promotion Department, WHO
18:50-19:00	• Operational Description of Rare Diseases	<b>Dr. Mary Wang</b> , Science Policy Manager, RDI
19:00-19:10	• 5 Proposals on Global Networking to Strengthen Health Systems for PLWRD	<b>Ms. Flaminia Macchia</b> , Executive Director, RDI
19:10-19:25	• Operational Framework for a Global Rare Diseases Network (GRDN)	<b>Mr. Matt Bolz-Johnson</b> , Programme Director RDI
19:25-19:35	• Equitable Engagement and Community Readiness	<b>Dr. Louise Clement</b> , Executive Director, Clinical Partnerships and Education Accreditation, HSO

19:35-20:15

## Panel Discussion on the Value of Networked Care Globally

### Perspective from Patient Groups

**Mr. Salman Saif**, CureforU  
**Ms. Lisa Sarfaty**, National Organization for Rare Disorders, USA

### Perspective from a Hospital Manager

**Mr. Per Joergensen**, Deputy Chief Executive, Rigshospitalet, Copenhagen University Hospital

### Perspective from Clinical Experts

**Professor Gareth Baynam**, Program Director, Undiagnosed Diseases Program-Western Australia  
**Professor Carmencita Padilla**, Chancellor, University of the Philippines Manila  
**Professor Johnny Mahlangu**, University of the Witwatersrand, South Africa

## Final Address & Closing

20:15-20:20	• <b>Final Address:</b> Cross-regional Collaboration to Support Health Equity	<b>Mr. Martin Seychell</b> , Deputy Director General at DG INTPA, European Commission <b>Mr. Yann Le Cam</b> , Chief Executive Officer, EURORDIS
20:20-20:30	• Closing Remarks & Take-home Messages	