



AGENDA

UHC FOR RARE DISEASES: DEVELOPING KEY PILLARS TOGETHER

Monday, 12 December 2022 | 14:00 to 15:30 (CET) | Online

14:00 – 14:10

Welcome and Opening Remarks

- Todd Howland, Chief of the Development and Economic and Social Issues Branch at the Office of the High Commissioner for Human Rights (OHCHR)

14:10 – 14:20

Keynote Address

- Dr. Surakameth Mahasirimongkol, Director, Genomics Medicine and Innovation Support (GeMIS), Ministry of Public Health, Thailand (Co-Sponsoring Country of UN Resolution on "Addressing the challenges of persons living with a rare disease and their families")

14:20 – 14:30

Financing UHC for Persons Living with a Rare Disease

- Smitha Sadasivan, Steering Committee of UHC2030

14:30 – 14:40

UHC for Rare Diseases: The Key Pillars from Civil Society

- Flaminia Macchia, Executive Director of Rare Diseases International (RDI)
- Dolores Cvitanin, Public Affairs Manager of RDI

14:40 – 15:25

UHC for Rare Diseases: The Regional Perspective Panel Discussion

- Roberta Anido de Pena, President of Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)
- Samuel Agyei Wiafe, Executive Director of Rare Disease Ghana Initiative
- Kin Ping Tsang, President of Rare Disease Hong Kong
- Daria Julkowska, Scientific Coordinator of the European Joint Programme on Rare Diseases and Coordinator of the International Rare Disease Research Consortium Secretariat

Discussion moderated by Dolores Cvitanin

15:25 – 15:30

Closing Remarks

- Durhane Wong-Rieger, Chair of RDI Council