



EVENT SUMMARY

UHC FOR RARE DISEASES: DEVELOPING KEY PILLARS TOGETHER

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

Universal Health Coverage (UHC) Day 2022

EVENT SUMMARY

On Universal Health Coverage Day 2022, the global community of Persons Living with a Rare Disease (PLWRD), alongside other stakeholders, defined UHC for rare diseases and identified the next steps towards making it a reality. In this context, the drive to advance the Political Declaration on UHC and the 2030 Agenda - in particular, Sustainable Development Goal 3 on Good health and wellbeing - was catalyzed.



Concept Note

Agenda



KEY MESSAGES FROM SPEAKERS



TODD HOWLAND (OHCHR)

"OHCHR reiterates its solidarity with all stakeholders in efforts to secure universal health coverage for PLWRD."



DR. SURAKAMETH MAHASIRIMONGKOL (MINISTRY OF PUBLIC HEALTH, THAILAND)

"We must immediately strengthen the effectiveness of national, regional, and international policy related to PLWRD."



SMITHA SADASIVAN (UHC2030)

"It is not enough to have policy. We need to reach the person at the ground level, so that this person gets informed and can access services. Civil society has a major role in doing this."



FLAMINIA MACCHIA (RDI)

"For the global community of PLWRD and their families, the time to act on the pledge in the Political Declaration on UHC from 2019 - which specifically mentions rare diseases - is now."

THE EVENT IN NUMBERS



289

REGISTERED



155+

ATTENDEES



7

MINISTRIES



1

UN BODY



5

UMBRELLA ORGANISATIONS



7

PERMANENT MISSIONS

WATCH THE REPLAY



DURHANE WONG-RIEGER (RDI)

"It is one thing to have a high-level policies. It's one thing to have countries broadly acknowledging and agreeing to support them. It's another thing to get them implemented."

MESSAGES FROM PANELISTS



ROBERTA ANIDO DE PENA (FADEPOF)

"The dissemination of specific health laws is a fundamental task to help the community. This is a task that we must carry out permanently."



SAMUEL AGYEI WIAFE (RARE DISEASE GHANA INITIATIVE)

"Mental health is a critical and important part of healthcare for PLWRD. We must bring attention to this concern."



KIN PING TSANG (RARE DISEASE HONG KONG)

"The government, business sector, and patient advocates must work together to cope with the burden of rare diseases."



DARIA JULKOWSKA (EJPRD, IRDIRC)

"Often the bottleneck is bringing the necessary expertise. So sharing expertise is extremely important."

KEY RECOMMENDATIONS

1

Invest meaningfully in Research and Development, and in health services for PLWRD.

2

Evaluate whether the current systems conform to human rights obligations.

3

Mainstream UHC into international, national, and regional legal and policy frameworks.

5

Ensure that PLWRD participate in policy making.

6

Establish mechanisms for the exchange of technical expertise, and the training of physicians and other health workers.

7

Treat human rights as part of the rule of law - the right to health is not optional.