



CONCEPT NOTE

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

CO-ORGANIZERS

Rare Diseases International (RDI) and the Civil Society Engagement Mechanism for UHC2030 (CSEM)

OVERVIEW

For the more than 300 million Persons Living with a Rare Disease (PLWRD) worldwide, the time to act on the commitment expressed in the Political Declaration on Universal Health Coverage is now. This document calls on the UN Member States to “Strengthen efforts to address rare diseases as part of universal health coverage”. Ensuring universal coverage for PLWRD means that this community has access to the healthcare services they need, with less or no out-of-pocket expenses. Addressing the challenges faced by the rare disease community includes respecting their fundamental human right to health and recognizing that their needs are linked specifically with the rarity of their condition, for which there is a lack of research and expertise. This situation leads to misdiagnosis, delay in diagnosis or no diagnosis at all: PLWRD wait an average of 5 years before they receive an accurate diagnosis. Development of and access to medicines and therapies is a global challenge, and in many countries, their high cost forces PLWRD to resort to less safe and effective alternatives, or to forego treatment altogether.

Health coverage will not be universal unless and until the needs of PLWRD are addressed.

THE OBJECTIVE OF THE EVENT

This UHC Day event will define UHC for rare diseases and identify the next steps towards making it a reality. Firstly, expert speakers will present what the global community of PLWRD and their families currently considers the main pillars of UHC for rare diseases. Then, panelists will bring particular examples, from their regions, of positive developments for PLWRD since the Political Declaration on Universal Health Coverage was adopted in 2019, while also mapping out detailed future steps towards its fulfillment. In this context, the drive to advance UHC for PLWRD will be catalyzed. Likewise, the 2030 Agenda, particularly Sustainable Development Goal 3 on Good health and well-being, and the UN Resolution on “Addressing the challenges of persons living with a rare disease and their families”, will be emphasized.

ABOUT RARE DISEASES INTERNATIONAL

RDI is the global alliance of Persons Living with a Rare Disease and their families. RDI is a network of 86 organizations representing patient groups active in over 150 countries worldwide. We are an official partner of UHC2030.