Engaging the UN System and Member States to Achieve Universal Health Coverage or Persons Living with a Rare Disease:

A Blueprint for Leaving No One Behind

Concept Note

Organizers
Permanent Mission of Spain to the United Nations and Rare Diseases International (RDI)

Co-Organizers
NGO Committee for Rare Diseases, EURORDIS-Rare Diseases Europe, and Federación Española de Enfermedades Raras (FEDER)

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 (UHC) is now. Ensuring universal coverage for PLWRD means that this often-neglected 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 to 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: in developed countries PLWRD wait an average of five 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.

It is in this context that RDI defines what UHC for Rare Diseases consists of, and how it can successfully be implemented globally, including in Low-or-Middle-Income Countries (LMICs) with resource-constrained health systems.

Objective of the Event
This event is the continuation of years-long advocacy by RDI and its partners. Since the Political Declaration on UHC in 2019, in which rare diseases are specifically mentioned, and the milestone UN Resolution on "Addressing the challenges of persons living with a rare disease and their families", RDI has solidified the key tenets of UHC for Rare Diseases through regional consultations. By looking at the three pillars of UHC in general, namely population, services, and financial protection, and applying them to rare diseases in particular, this event will solidify the next steps in implementing UHC for Rare Diseases.

Engaging the UN System and Member States to Achieve UHC for PLWRD: A Blueprint for Leaving No One Behind will feature expert speakers, panellists, and an audience formed of civil society, academia, research and health institutions, government ministries, regional and international organizations, and the private sector.

The speakers and panellists will, moreover, highlight the specific needs of the global community of PLWRD, address the burden unpaid caregivers (who are most often women) currently bear, and explore methods to reduce the out-of-pocket expenses (OOPs) shouldered by PLWRD and their families. These themes are in line with the World Health Organization’s Thirteenth General Programme of Work and its first Triple Billion Target, and RDI’s four-year long successful collaboration with the WHO under a Memorandum of Understanding. Furthermore, in this way, an intersectional approach which addresses several Sustainable Development Goals (SDGs) – with a focus on SDG 5, Gender equality - will advance the push towards achieving UHC for PLWRD by 2030, as stipulated in the 2030 Agenda.