



RARE  
DISEASES  
INTERNATIONAL



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FEDERACIÓN ESPAÑOLA DE ENFERMEDADES RARAS



NGO COMMITTEE FOR  
RARE DISEASES

**Statement delivered by Yann Le Cam at the High-Level Meeting on Universal Health Coverage on the overall theme of “Universal health coverage: expanding our ambition for health and well-being in a post-COVID world” - United Nations Headquarters New York - 21 September 2023.**

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*Formal statement on behalf of the NGO Committee for Rare Diseases (CONGO), EURORDIS-Rare Diseases Europe (ECOSOC “EURORDIS European organisation for Rare Diseases”), Agrenska (ECOSOC), Rare Diseases International (RDI) and the Federación Española de Enfermedades Raras (FEDER)*

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The global rare disease community, represented by EURORDIS-Rare Diseases Europe, in the name of Rare Diseases International, welcomes the opportunity to make a joint statement at this High-Level Meeting. We strongly support the 2023 UN Political Declaration on UHC, in which rare diseases are included. We urge UN Member States to adopt this document, and further efforts to implement UHC for Persons Living with a Rare Disease, building on the political momentum generated by the UN Political Declaration from 2019, and the UN Resolution on “Addressing the challenges of persons living with a rare disease and their families”, adopted by consensus at the UN General Assembly on 16 December 2021.

Each rare disease affects a small number of patients in each country but, when considered all together, the 6000+ rare diseases are affecting a minimum of 4% of the population in each country, and 300 million people worldwide.

Rare diseases are genetic disorders, rare bacterial or viral infections, rare poisonings and rare cancers. In 70% of cases, rare genetic disorders appear during childhood. Rare diseases are chronic, complex, progressive, disabling, and life-threatening. Many people affected live in the margins of society, often undiagnosed, unrecognized, and unable to access services available to common conditions. These factors impact family finances and mental health, and are detrimental to their active participation in society. As such, people living with a rare disease constitute a vulnerable and neglected population, mostly invisible to the system regardless of their own socio-economic circumstances, and of the level of development of the country.

Even with existing resources, strategies securing the three aspects of UHC can translate into more services, covering more Persons Living with a Rare Disease, and with the reduction of sometimes catastrophic out-of-pocket expenditures for Persons Living with a Rare Disease and their families, are a reality. To leverage the political commitment vis-à-vis including Persons Living with a Rare Disease in UHC, we need a global framework for



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action for rare diseases, which capitalizes on this political will, producing funding and resources to improve lives of Persons Living with a Rare Disease. This can best happen with a World Health Assembly Resolution addressing the matter.

The efforts to accelerate and implement UHC, globally, and with a human rights-centered approach, will not achieve the goal of the 2030 Agenda, namely of leaving “No One Behind”, until all Persons Living with a Rare Disease are robustly included in Member States’ UHC packages.