



United Nations High-Level Meeting on Universal Health Coverage

Engaging the UN System & Member States to Achieve Universal Health Coverage for Persons Living with a Rare Disease: A Blueprint for Leaving No One Behind

A Formal Side Event Co-Sponsored by Spain, Sweden and Qatar

21 September 2023
UN Headquarters, New York City

Meeting Report



RARE
DISEASES
INTERNATIONAL



feder
FEDERATION OF EUROPEAN
DISEASE ASSOCIATIONS



NGO COMMITTEE FOR
RARE DISEASES

Summary

On 21 September, 2023 UN Member States gathered at a High-Level Meeting at the UN Headquarters in New York to accelerate progress towards achieving Universal Health Coverage (UHC) by 2030. In conjunction with this momentous occasion, Rare Diseases International (RDI), EURORDIS – Rare Diseases Europe, Ågrenska, Federación Española de Enfermedades Raras (FEDER) and the NGO Committee for Rare Diseases held a formal side-event to emphasize the vital importance of including the rare disease community in UHC.



Co-sponsored by Spain, Sweden and Qatar, the event underlined the message that UHC cannot be truly universal and leave no one behind unless it meets the needs of the 300 million people worldwide living with a rare disease.

The event was formally opened by Her Majesty the Queen Letizia of Spain and Her Majesty the Queen Silvia of Sweden, followed by addresses from the Ministers of Health of Sweden, Qatar, France, Malaysia, as well as representatives from the Ministries of Health of Canada and Brazil, the Ministry of Foreign Affairs of the United Arab Emirates, and the European Commission, emphasizing the need for global action on supporting PLWRD through sharing expertise, investing in scientific research, and relieving the economic burden of rare diseases.

A World Health Organization Resolution would entail the necessary commitment from the member countries to share the actions that are already under way and lay down a firmer common path towards equity.

Her Majesty the Queen
Letizia of Spain



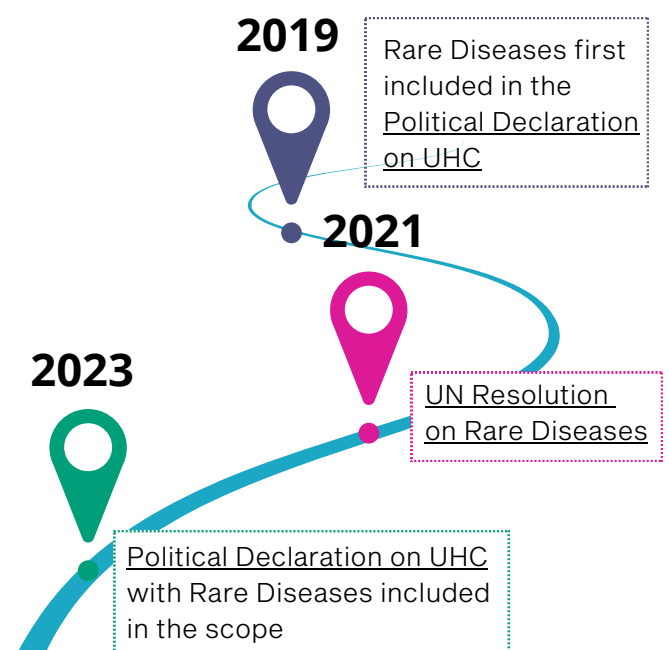


Sharing knowledge, and gathering new scientific information, as well as medical cooperation, on an international level, is crucial to envisage a brighter future for people living with a rare disease – and, of course, for their families.

Her Majesty the Queen Silvia of Sweden

Dr. Jérôme Salomon, Assistant Director-General of the World Health Organization, along with speakers from the World Bank, the Office of the UN High Commissioner for Human Rights (OHCHR), the NGO Committee for Rare Diseases, and the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO) highlighted the need for supporting the rare disease community as part of their objectives of supporting global human rights and sustainability.

The high-level, global participation in this event reflects the political momentum for rare diseases that has been growing since the 2019 Political Declaration on UHC, which marked the first time that rare diseases were included in a UN declaration adopted by all 193 Member States. This was followed by the first-ever UN resolution on rare diseases in 2021. The meetings provide further evidence that the UN Member States are collectively committed to supporting the rare disease community with the objective of meeting their complex needs.



However, this commitment alone is not sufficient. This global commitment must now be translated into action at the regional and national levels. For the more than 300 million Persons Living with a Rare Disease (PLWRD) worldwide, the time to act on the Political Declaration on Universal Health Coverage is now.

The WHO has reported that there are over 7000 rare diseases, and it is our responsibility to coordinate a response that **safeguards the well-being of patients and their families.**

His Excellency
Dr José Manuel Miñones Conde
Minister of Health, Spain



The medical, social and financial challenges faced by PLWRD were underlined during a panel of patient advocates from four different continents, moderated by Durhane Wong-Rieger, Chair of the Council of RDI and President of the Canadian Organization for Rare Disorders. During the panel, patient advocates spoke of issues such as delays in diagnosis, limited access to services, and the high cost of treatments.



The patient advocates emphasized that the financial burden of rare diseases is not limited to medical expenses: PLWRD and their families bear significant costs associated with their complex needs, including transportation and rehabilitation

Coupled with the lost income of family members serving as caregivers, who are disproportionately women, this creates a long-term financial burden, leading to the impoverishment of the rare disease population. For society, the cost of not diagnosing and not treating rare diseases exceeds the cost of timely appropriate services.

“We do not come to say ‘we need you to do something for us.’ Because rare disease patients, health care providers, the communities are coming in with solutions, with opportunities. And what we can do is contribute back to the society, to the health systems. And most importantly, **we can help contribute to the achievement of the sustainable development goals for the UN.**”



Durhane Wong-Rieger
Chair, RDI Council
President, CORD



France supports the ongoing discussions on the adoption of a **resolution by the World Health Assembly** in 2025 to provide a framework for health equity and strengthening of healthcare systems for rare disease. ”

His Excellency Aurélien Rousseau
Minister of Public Health and Prevention, France

To address these challenges effectively, governments must respect the fundamental human right to health of PLWRD and recognize that their needs are linked specifically to the rarity of their condition. While each rare disease only affects a small number of people, together there are over 7000 rare diseases affecting 4% of the population of every country in the world.



Without addressing the challenges of this vulnerable population, Universal Health Coverage cannot succeed.

That is why, in the words of Alexandra Heumber Perry, CEO of RDI:



RDI and its partners are calling on member states to mobilize efforts to provide a global framework for action, through the adoption of a World Health Assembly Resolution on Rare Diseases. Now is the time to **capitalize on the political will of this moment** to improve the lives of People Living with a Rare Disease through adequate funding and resources to ensure that Universal Health Coverage truly leaves no one behind. ”

Alexandra Heumber Perry
Chief Executive Officer, RDI

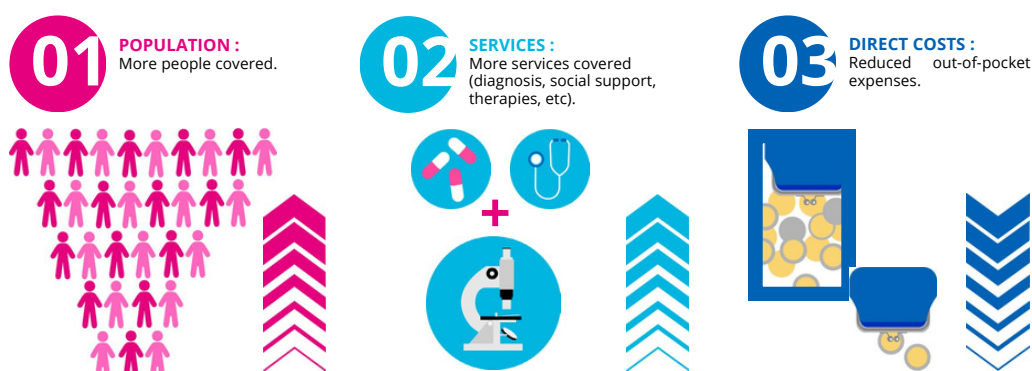


Objectives

Universal health coverage (UHC) ensures all people, everywhere, can access the quality essential health services they need without being exposed to financial hardship.

Member States need to consider three dimensions of coverage when moving toward universal health coverage: in terms of population, in terms of services, and in terms of proportion of costs covered: population, services, and direct costs.

THE THREE DIMENSIONS OF UNIVERSAL HEALTH COVERAGE



[More detailed information on the three dimensions \(WHO\)](#)

It is in this context that Engaging the UN System and Member States to Achieve Universal Health Coverage for PLWRD: A Blueprint for Leaving No One Behind:

- Recalled the importance of “no UHC without PWLRD covered”
- Built greater political momentum for policymakers to address the multifaceted challenges experienced by PLWRD in healthcare systems.
- Highlighted the national successful actions implementing UHC for rare diseases;
- Outlined high-impact actions for policy makers and stakeholders to implement;
- Called for more ambitious actions to make UHC a reality for PLWRD, notably the adoption of the WHA resolution of rare diseases, which would, for the first time, deliver a global framework for actions at regional and national levels.



In general health systems are not adapted to rare diseases and there is little public health policy to respond to their specific needs. But universal health coverage means that **all people and communities receive the healthcare they need** of sufficient quality to be effective, while also ensuring that they do not have to choose between healthcare or a meal on the table. ”

Dr Jérôme Salomon, Assistant Director-General, WHO



“ We recently announced that we will begin work to develop a **national strategy** for people living with rare diseases...Sweden is a small country and we cannot solve all the challenges that exist for PLWRD by ourselves, so we welcome cooperation and exchange of best practices across national borders. Patients should not be forced to travel, but **knowledge** should. ”

Her Excellency Acko Ankarberg Johansson
Minister of Health Care, Sweden



Universal Health Coverage for PLWRD: A Blueprint for Leaving No One Behind High Impact Actions for Policymakers

- Prioritize and integrate rare diseases within regional and national UHC plans.
- Create a national plan or strategy for rare diseases.
- Develop national sustainable programs dedicated specifically to undiagnosed diseases, supported by appropriate authorities in every country to enable rapid and equitable access to diagnosis and social support
- Encompass a multidisciplinary approach which mobilizes and builds the capacities of healthcare providers from different sectors.
- Include services which treat the complex needs of PLWRD.
- Address the oftentimes catastrophic costs shouldered by PLWRD and their families.
- Institute a specific funding stream for rare diseases.
- To promote, through existing initiatives, ethical and responsible international data sharing to support diagnosis, increase clinical collaboration, facilitate research, and accelerate treatment of undiagnosed and rare conditions
- Increase education of rare diseases in schools and public fora to dispel stigma and discrimination.



The scarcity of expertise, specialized centers, and the accompanying economic burdens necessitate **open communication and collaboration** among regional and international scientific institutions. ”



Her Excellency Dr. Hanan Mohamed Al Kuwari
Minister of Public Health, Qatar

Key Messages



“The commitment of the EU and its Member States to Universal Health Coverage at the United Nations General Assembly and its support for the inclusion of rare diseases goes far beyond the European Union. It signals that the EU is ready to partner with WHO Europe to **support rare diseases policy and actions across Europe**, through WHO and all its Member States. ”

Yann Le Cam
Chief Executive Officer, EURORDIS-Rare Diseases Europe
RDI Founder, Treasurer, and Policy Committee Chair



For people living with a rare disease, having access to the right drug, at the right time could **improve quality of life** and can provide peace of mind to them and their families. ”

Her Excellency Dr. Theresa Tam
Chief Public Health Officer, Canada



I want to invite everyone to really understand **human rights' relevance** to the issue of rare diseases, to access to drugs and medicines. ”

Todd Howland
Chief, Development and Economic
and Social Rights Branch, OHCHR



It's possible to set up a **win-win game**. For this we need to change our mindset, our culture, our public policies and business models. ”

His Excellency Carlos Graboia Gadelha
Minister of Science, Technology, Innovation and
the Health Economy Industrial Complex, Brazil



As a forward thinking nation, the United Arab Emirates firmly believes that access to **quality healthcare is not a privilege**, but a fundamental human right. ”

Her Excellency Dr. Maha Barakat
Assistant Minister for Medical Affairs and Life Sciences,
United Arab Emirates



The problems we are facing need **urgent solutions**. 300 million people and their families depend on this. The delay of diagnosis is up to 4 years in Europe and even longer in other locations. 6% of the rare diseases that we know have treatment and the access to it is not equal for all. ”

Juan Carrión Tudela
President, FEDER and ALIBER



Only a **holistic approach** to the needs of each child or adult living with a rare disease can enable his or her full potential for lifelong inclusion in society. ”

Anders Olauson
Chairman, Agrenska and
NGO Committee for Rare Diseases



We recognize that **rare diseases are a market failure that require increases in financing from government**, but government cannot do it alone. We need donor financing, philanthropies, private sector and all parties. In the prioritization process by governments such as discussions around benefit packages or budget, governments need to explicitly introduce principles of equity. ”

Dr. Sarah Alkenbrack
Senior Health Economist, World Bank





True Universal Health Coverage can only be achieved through meaningful collaboration that break barriers to participation at all levels of stakeholders involved; when the needs of the vulnerable including people living with rare diseases are not swept aside with tokenism, and policies are driven and matched with real and sustainable action on-ground. ”

Nadiah Hanim Abdul Latif
President, Malaysian Rare Disorders Society

We need to collaborate with every institution in health, social welfare and local services to be able to provide holistic care, holistic support for families. ”

Vlasta Zmazek
President, DEBRA Croatia



It is important that any government which develops a plan to improve the health system involves the patients and patient organizations in constructing their methods and approaches, because it's important for the patients to be involved in that leadership process. ”

Diego Fernando Gil Cardozo
Executive Director, FECOER

What started as a fight for my children, has become a fight for all Kenyans living with a rare disease. ”

Christine Mutena
Co-Founder, Rare Disorders Kenya

In China, being such a big population with 30 million rare disease patients, the key is prioritization. To that end, China has released the rare disease catalogue. The list really serves as a prioritized implementation plan. ”

Rachel Yang, Head of International Affairs
China Alliance for Rare Diseases





Health is the true commonwealth. Universal health care must be common and a global common good, deserving of more public funding as a life-giving value compared to wars, that today receive more public funding.

Liberato C. Bautista
President, CoNGO



Critical needs are not confined to health and access to orphan drugs alone. I strongly invite leaders from the pharmaceutical industries, academia and corporations to join in.

Let's do this together. Let's do this better.

Her Excellency Dr. Zaliha Mustafa
Minister of Health, Malaysia



5 Ministers of Health



4 High-Level Representatives of State



2 UN Agencies



3 International Institutions



Patient Advocates from 5 Countries



100 in-person attendees



1,500 video views

Agenda

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