

Public Webinar: Towards a WHA Resolution on Rare Diseases

Towards a World Health Assembly Resolution on Rare Diseases 2025 Public Webinar *Co-hosted by the Arab Republic of Egypt, the State of Qatar, and Spain*

Friday, 30 August 2024
14:00 – 15:30 (CEST) – Online (Microsoft Teams)

Background

As Rare Diseases International continues to build off momentum generated at their side event at the 77th World Health Assembly (WHA), this webinar aims to further advocate for a World Health Assembly Resolution on Rare Diseases in 2025. With the Arab Republic of Egypt, the State of Qatar, and the Kingdom of Spain officially sponsoring the WHA Resolution, this webinar seeks to secure further international support for the resolution. Getting additional Member States to support and co-sponsor the Resolution is essential to ensuring the prioritization of rare diseases on the global health agenda and improving access to diagnosis, treatment, and support services for affected individuals worldwide.

In collaboration with Egypt, Qatar, and Spain Member States have a unique opportunity to be leaders in addressing an existing unmet need in healthcare by shedding light on the challenges faced by the more than 300 million PLWRD and proposing solutions for a better ecosystem for rare diseases. This will lead to significant returns on investment in science and technology, policy guided by principles of equity and empowerment, the strengthening of health systems for increased access to diagnosis and care, and improved resources for the social systems that support PLWRD and their families.

Despite considerable progress, including the recognition of rare diseases within the United Nations (UN) 2030 Agenda for Sustainable Development, which seeks to promote health equity by addressing the needs of the most vulnerable populations, PLWRD continue to face substantial challenges globally, such as delays in diagnosis, difficulties in accessing treatments and services, social stigma, and financial burdens. Currently, 6,000+ rare diseases have been named and described. Of these 6000 diseases, the 400

most prevalent affect an estimated 90% of the population living with a rare disease; there is a very long tail of extremely rare diseases.¹⁻²

In 2019, UN Member States adopted the United Nations Political Declaration on UHC, which includes rare diseases (Resolution A/RES/74/2, 2019). This declaration was renewed in September 2023 with the Political Declaration of the High-Level Meeting on UHC (Resolution A/RES/78/4, 2023).³

In December 2021, a major turning point in the global political landscape was achieved when the UN General Assembly unanimously adopted the UN Resolution Addressing the Challenges of Persons Living with a Rare Disease and their Families (Resolution A/RES/76/132, 2022). The 2021 UN Resolution paves the way for greater integration of rare diseases into the agenda and priorities of the UN system. **However, a framework for coordinated action with all stakeholders and Member States is needed to translate these commitments into action and overcome the barriers to accessing diagnosis, treatment, and care for PLWRD to ensure no one is left behind in the pursuit of UHC.**

The vast challenges of treating PLWRD cannot be resolved by a single country or entity. They can only be addressed by a global, multidisciplinary, and collaborative approach. “Leaving no one behind” can become a reality if Member States, in line with the 13 and 14 World Health Organization (WHO) General Programme of Work, adopt a **resolution on rare diseases at the 78th WHA**. This will secure rare diseases as a **priority on the global health agenda and emphasize to Member States the importance of addressing the social and financial burdens of treating PLWRD in a sustainable and inclusive way so that people with rare diseases are not left behind in the work on UHC.**

Event Objective

The main objective of the event is to engage all attendees, including representatives of permanent missions, WHO representatives, rare diseases organizations, and interested

¹ Nguengang Wakap, S., Lambert, D. M., Olry, A., Rodwell, C., Gueydan, C., Lanneau, V., ... & Rath, A. (2020). Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. *European Journal of Human Genetics*, 28(2), 165-173. <https://doi.org/10.1038/s41431-019-0508-0>

² Haendel, M., Vasilevsky, N., Unni, D., Bologna, C., Harris, N., Rehm, H., ... & Oprea, T. I. (2020). How many rare diseases are there?. *Nature reviews drug discovery*, 19(2), 77-78. <https://doi.org/10.1038/d41573-019-00180-y>

³ UN General Assembly (76th sess.: 2021-2022). Addressing the challenges of persons living with a rare disease and their families: resolution / adopted by the General Assembly, A/RES/76/132.

members of the general public in a discussion on **why it is critical to adopt a WHA Resolution on Rare Diseases in 2025**. The webinar provides an opportunity to inform and respond to attendees' questions about the resolution initiative in order to build support in the lead up to the WHO Executive Board meeting in January 2025.

Target Audience

The following stakeholders form the target audience for the event:

- Representatives of Geneva permanent missions and Ministries of Health
- Policy Makers
- Global health organizations
- Private sector
- Representatives of RDI members
- Patient Advocates
- Members of the general public

Draft Agenda

Time	Topic
2:00pm-2:05pm	Welcoming the participants on-line + housekeeping + overview of session agenda
2:05pm-2:10pm	Opening Remarks: Alexandra Heumber Perry – CEO, Rare Diseases International
2:10pm-2:35pm	Opening Remarks by Member States <ul style="list-style-type: none"> - Professor Mohamed Hassany, Assistant Minister for Public Health Projects and Initiatives, Ministry of Health and Population, Arab Republic of Egypt - Dr Mohamed Al-Thani, Director of Non-Communicable Diseases Prevention Programs Department, Ministry of Public Health, State of Qatar - Dr Mónica García Gómez, Minister of Health, Ministry of Health, Spain
2:35pm-2:50pm	Perspectives from Key Stakeholders in the Rare Disease Ecosystem Speakers: Dr Ghada El-Kamah, Professor of Clinical Genetics, National Research Centre, Egypt



	<p>Dr Ruediger Krech, Director of Health Promotion, World Health Organization (WHO)</p> <p>James Anderson, Executive Director of Global Health, International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)</p>
2:50pm- 3:10pm	<p>RDI Members Perspectives: What does the Resolution mean for RDI Members and for PLWRD?</p> <p>Speakers:</p> <p>Nthabeleng Ramoeli, Founder and CEO, Rare Diseases Lesotho Association</p> <p>Nadiah Hanim Abdul Latif, President, Malaysian Rare Disorders Society</p> <p>Juan Carrión, President, FEDER</p> <p>Antoine Daher, President, Casa Hunter</p>
3:10pm- 3:25pm	<p>Short remarks from key participants & Questions</p>
3:25pm- 3:30pm	<p>Closing Remarks: Alexandra Heumber Perry – CEO, Rare Diseases International</p>