

11 February 2025

A Significant Milestone for the WHA Resolution on Rare Diseases

RDI applauds the decision of the 156th WHO Executive Board (EB) to recommend the adoption of the Resolution on Rare Diseases to the 78th World Health Assembly (WHA) in May 2025. This marks a significant milestone in the global effort to improve the lives of over 300 million persons living with a rare disease (PLWRD) worldwide.

With 26 Member States co-sponsoring the resolution and 224 organizations across the globe uniting in a Coalition to support it, this strong momentum reflects the growing recognition of rare diseases as a global health priority.

Concerns around the financing of new initiatives resulted in the decisions on advancing several new Member State initiatives and resolutions being put on hold until their costs could be more fully assessed. During discussions concerning WHO's budget and finance matters for the term 2026-2027, Member States highlighted the importance of equity and strategic resource allocation in achieving Universal Health Coverage (UHC) and the Sustainable Development Goals. Member States expressed their support for the adoption of resolutions and emphasized the critical importance of ensuring financial sustainability in implementation. Member States decided to request that the implementation of new resolutions take into account the operationalization of the Programme budget through a prioritization process. The Resolution on Rare Diseases under the UHC agenda item was then recommended for adoption to the 78th WHA.

RDI would like to express its gratitude towards the Arab Republic of Egypt and Spain for their leadership in initiating the process towards this landmark achievement, and to all the Member States co-sponsors — Brazil, Chile, China, Ecuador, France, Greece, India, Iraq, Jordan, Kuwait, Luxemburg, Malaysia, Pakistan, Palestine, Panama, Philippines, Qatar, Romania, Russia, Slovakia, Slovenia, Somalia, Thailand, and Vanuatu — as well as to the WHO for successfully advancing the Resolution to the 78th WHA.

In addition, RDI thanks its members, the over 200 members of the Coalition in Support of the Resolution on Rare Diseases, and all members of the global rare disease community who joined in our effort.

The EB's landmark decision marks the first critical milestone towards our final objective of securing the adoption of the WHA Resolution on Rare Diseases and the Global Action Plan (GAP) at the upcoming 78th WHA.

The Coalition in Support of the Resolution on Rare Diseases is fully prepared to support the implementation of the Resolution upon its adoption in May and, most importantly, to advance the development of the GAP. This is urgently needed to provide national governments with a tangible framework for action with clear targets and accountability measures to reach the Global Health 2035 Goals and to make UHC a reality.

The adoption of the WHA Resolution on Rare Diseases will cement rare diseases as a priority on the global health agenda and affirm the recognition of the unique challenges and inequities faced by PLWRD worldwide in accessing appropriate care and support. The Resolution will

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emphasize the critical need to address the social and financial burden of living with a rare disease, providing PLWRD and their families with the visibility and recognition they deserve. The next step is to translate the Resolution into action by all stakeholders and Member States to overcome the barriers in accessing diagnosis, treatment, and care for PLWRD ensuring a more equitable and sustainable treatment of rare diseases.

RDI urges Member States of the WHA to maintain their commitment and collaboration to secure the adoption and the implementation of the WHA Resolution on Rare Diseases and the GAP.