

Towards a WHA Resolution on Rare Diseases & Global Action Plan

Why a World Health Assembly Resolution & Global Action Plan?

This is a pivotal moment in global health. Member States have the opportunity to **transform the lives of the over 300 million persons living with a rare disease** (PLWRD), millions of people living with an undiagnosed disease (PLWUD), and their families and caregivers.

In February 2025, thanks to the outreach efforts of the co-sponsors and the Coalition, the WHO Executive Board officially **recommended the Resolution on Rare Diseases for adoption by the 78th WHA**. The Resolution, "Rare diseases: a global health priority for equity and inclusion," underlines the need for **a comprehensive approach to rare diseases, ensuring equitable access to diagnosis, treatment, and care**. Namely, it calls on the WHO Director General to develop a Global Action Plan on Rare Diseases.

What are the challenges facing PLWRD?



Collective Action for Common Challenges

The Arab Republic of Egypt and Spain have led the development of a landmark **WHA Resolution calling for the development of a Global Action Plan on Rare Diseases (GAPRD)**. **Global momentum behind the WHA Resolution on Rare Diseases continues to grow**. The Resolution is now co-sponsored by 24 other Member States.

Over 240 patient associations, research centres and healthcare institutions have also affirmed their support by joining a Coalition in support of the WHA Resolution.

Rare Disease:
A medical condition that affects fewer than 1 in 2,000 persons

3-8% of the global population is affected by a RD

Over **7,000 rare conditions** have been identified

95% of rare diseases have **no approved treatment**

PLWRD wait up to **5 years** on average for a **correct diagnosis**

What needs to happen next?

We call upon the WHA to:

ADOPT THE RESOLUTION ON RARE DISEASES



Formalize commitment at the national level to the WHA's call for a Global Action Plan on Rare Diseases

DEDICATE RESOURCES FOR IMPLEMENTATION



Ensure sufficient sustainable resources to implement the Resolution and develop the GAPRD

ESTABLISH A CONSULTATION PROCESS



Elaborate a comprehensive engagement plan in collaboration with Non-State Actors representing PLWRD and other relevant stakeholders, communities & civil society

29
Member State Co-sponsors

Bahrain, Brazil, Chile, China, Colombia, Ecuador, El Salvador, Egypt, France, Greece, Guatemala, India, Iraq, Jordan, Kuwait, Luxemburg, Malaysia, Pakistan, Palestine, Panama, Philippines, Qatar, Romania, Russia, Slovakia, Somalia, Spain, Thailand & Vanuatu

265+
Coalition Members - civil society and academic organizations

Towards a WHA Resolution on Rare Diseases & Global Action Plan

What will the Resolution do?

The WHA Resolution on Rare Diseases has the potential to elevate the visibility of both rare and undiagnosed diseases on the global health agenda, creating pathways for earlier and more accurate diagnoses and expanded treatment, care and support. In addition to calling for the development of a GAPRD, **the Resolution calls upon Member States to:**

- 01 Commit to actions that enhance support for rare diseases, including policy development, integration into health plans, and awareness campaigns
- 02 Mobilize resources and explore innovative funding models, particularly for developing countries
- 03 Encourage the creation of National and Regional Centers of Excellence for research, training, and care in rare diseases
- 04 Encourage the establishment of national rare disease registries to collect and analyze data
- 05 Foster collaboration across policymakers, academia, the private sector, and civil society to drive research and innovation in diagnosis and treatment

The adoption of the Resolution on Rare Diseases at the 78th WHA will **secure rare diseases as a global health priority** and address the social and financial burdens of treating PLWRD and PLWUD in a sustainable and inclusive way, so that **no one living with a rare or undiagnosed disease is left behind in UHC.**

Find additional resources, information, and RDI's full **WHA Resolution Toolkit** here:



What will the GAPRD do?

The WHA Resolution requests the WHO Director General develop, in consultation with Member States, and in collaboration with relevant NGOs and academic institutions, **a comprehensive 10-year Global Action Plan on Rare Diseases** by the 80th WHA. This Global Action Plan should:



Act as a catalyst for systemic change by providing Member States with a practical framework for action, tailored to their level of progress



Ensure policies and practices are grounded in the best available evidence & that rare diseases are integrated into global health priorities like primary healthcare and UHC



Provide a clear & detailed road map for all stakeholders, promoting interdisciplinary and intersectoral approaches to establish global targets and strategic goals, along with specific actions to achieve them

By adopting and implementing the WHA Resolution on Rare Diseases, we can work towards a future where PLWRD and PLWUD receive the care, support, and recognition they deserve.