

SPAIN CO-SPONSORS THE WORLD HEALTH ASSEMBLY “RESOLUTION ON RARE DISEASES: A PRIORITY FOR GLOBAL HEALTH EQUITY AND INCLUSION” IN 2025



- » Of the 194 Members of the World Health Organization, Spain is one of the three countries, so far, that cosponsors the World Health Assembly (WHA) “Resolution on Rare Diseases: A Priority for Global Health Equity and Inclusion”, which seeks to ensure the prioritization of rare diseases on the global health agenda and improving access to diagnosis, treatment, and support services for affected individuals worldwide.
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- » This initiative has been initiated by the Arab Republic of Egypt, joined so far by the State of Qatar and Spain, with support from Rare Diseases International and national alliances such as FEDER.
- » Spain is thus doubly involved - from the Government and from the patient community - with the promotion of this initiative that seeks to curb inequity in access to health resources around the world.

August 21, 2024 – Achieving a World Health Assembly “Resolution on Rare Diseases: A Priority for Global Health Equity and Inclusion” by 2025: this is the main objective of the international and national patient movement represented by Rare Diseases International (RDI) and FEDER, the Spanish Federation of Rare Diseases. An objective that is now formally joined by the Spanish Ministry of Health.

It is estimated that more than 300 million people live with rare diseases or are seeking diagnosis worldwide. A group as broad as it is heterogeneous but that shares a common problem that ranges from diagnostic delay - which only on average in Spain exceeds 6 years - to access to treatment - since only 6% of rare diseases have them - through social difficulties such as achieving comprehensive care, having the necessary support products or educational and labor inclusion.



In this context, many countries and regions have promoted public policies that are increasingly capable of addressing this reality, as is the case in Spain with the Rare Diseases Strategy of the National Health System, which, in fact, has recently been evaluated. However, these policies have different degrees of implementation in different parts of the world, evidencing a great disparity in access in equity to available resources, both health and social.

For this reason, the international patient movement represented by RDI, is calling for a Resolution of the World Health Assembly on rare diseases, aware that this will help to promote greater investment and commitment to sharing resources and experience among Member States, which will be able to collect information on them to have an exact x-ray of the magnitude and difficulties of the group and, consequently, implementing measures that enable equitable access to available health resources, thus guaranteeing Universal Health Coverage.

An involvement that goes beyond the WHO

This WHA Resolution has been initiated by the Arab Republic of Egypt, joined so far by the State of Qatar and Spain, with support from Rare Diseases International and national alliances such as FEDER, making our country doubly involved: from the Government and from the patient community.

An involvement that has been going on for a long time, with our country also being one of the promoters of the United Nations Resolution on Rare Diseases approved in 2021 and updated in 2023. An initiative that paves the way for a greater incorporation of these diseases into the priorities of the United Nations. However, a further step is still needed on health to achieve coordinated action with all stakeholders and Member States that translates these commitments into action and overcomes the barriers of rare diseases.

Because, in addition, it is necessary to coordinate existing initiatives and put them at the service of patients and other territories because "this will have an impact in Europe, but also in other parts of the world such as Latin America, where there is still a great lack of equity in access to available resources," said the president of FEDER focusing on more difficult and heterogeneous realities.

International debate on August 30

The news comes a few days before the webinar 'Towards a Resolution of the World Health Assembly on Rare Diseases 2025' led by RDI on August 30 and in which more than 200 people are expected to participate. Among them, Juan Carrión himself, President of FEDER and its Foundation, who already represented the group at the United Nations in September 2023 in New York and this past May in Geneva together with David Sánchez, of the FEDER Board of Directors and its International Action Board.

On this occasion, the opportunities offered by this Resolution will be discussed among representatives of the World Health Organization itself, governments, the patient community and the private sector from around the world.