WHO Executive Board 156th session

Rare Disease Resolution and equitable access

Thank you, Chair, for the opportunity to speak.

On behalf of the Fundación Salud por Derecho. Rare diseases affect an estimated 350 to 475 million people worldwide, yet remain largely neglected in global health policy. Treatments exist for only 5% of the known 7,000–8,000 rare diseases. Patients, particularly in low- and middle-income countries, continue to face systemic barriers to timely diagnosis, affordable treatment, and equitable healthcare access.

While pharmaceutical innovation in rare diseases is advancing, high prices—reaching up to $4.25 million per treatment—render these medicines inaccessible for most. The current system relies on national and regional public incentives and subsidies, providing long market exclusivity periods, without ensuring global access, net-price transparency or transparency of cost of production, development and supply.

Furthermore, in those cases where countries have tried to make use of the flexibilities included in the Trade-Related Aspects of Intellectual Property Rights Agreement, to expand access to these therapies, they have faced massive political pressure by States and Non-State Actors (See, for instance Colombia's attempt to issue a compulsory license on imatinib mesylate).

All in all, the system does not protect the right to health and widens the gap between innovation and access. Member States and WHO must take urgent action to ensure that the underlying causes of access inequities are addressed in the Resolution and therefore in a potential Global Action Plan. This is key to ensure universal health coverage for people living with rare diseases (PLWRD).

Therefore, we urge Member States and the WHO to ensure that a resolution and a Global Action Plan for rare diseases includes language on the following issues:

1. The need to ensure that national and regional market incentives help ensuring globally equitable access to affordable medicines and diagnostics for rare diseases.
2. The promotion of transparency in medicine pricing, including production and research and development costs.
3. The need to protect countries' rights to use TRIPS flexibilities to enhance equitable access to rare disease medicines.
4. Strengthened collaboration to improve global availability of treatments through knowledge and technology transfer.

This resolution is a critical opportunity to move beyond symbolic recognition and towards concrete actions that ensure no person living with a rare disease is left behind.

Thank you.