



Media statement

EURORDIS responds to ENVI MEPs' latest debate on pharmaceutical reforms

7 November, Brussels – EURORDIS-Rare Diseases Europe has welcomed contributions delivered by MEPs this morning at the European Parliament Environment, Public Health and Food Safety (ENVI) Committee's debate on revisions to the EU's general pharmaceutical legislation.

This morning, members of the ENVI Committee discussed the 'pharmaceutical package' reform proposals, examining draft reports by MEP Tiemo Wölken (S&D, Germany) on the Regulation and MEP Pernille Weiss (EPP, Denmark) on the Directive.

Responding to remarks delivered during the ENVI Committee debate, as well as specific proposals of amendments to the proposed reforms, **Simone Boselli**, Public Affairs Director at EURORDIS, said:

"We at EURORDIS-Rare Diseases Europe cautiously welcome the recent draft reports from MEP Tiemo Wölken and MEP Pernille Weiss, which partially capture a collective will to drive healthcare innovation for rare diseases across Europe. We underline the pressing need for alignment with 'upstream' efforts to improve research with 'downstream' improvements in patient access to medicines.

"Today's ENVI Committee debate contributions indicate a shared dedication to improve access to affordable medicines for rare disease patients. The growing consensus on structured patient involvement across the medicinal life-cycle is particularly heartening. Our advocacy for genuine patient engagement aims to ensure that their voices shape policy, research and development of therapies, creating a truly patient-centric healthcare system within the EU.

"Clarity on 'high unmet medical needs' remains critical for our community. We support the upward modulation of incentives, such as concerning market exclusivity, which is necessary to respond to the diverse needs of our community, and to enhance the competitiveness of the European ecosystem for rare diseases. We endorse amendments promoting medicine accessibility, for example, through common procurement and swift access through PRIME, signalling a move towards a unified European health system.

"The recognition of the urgent need for a European Action Plan for Rare Diseases is especially commendable, promising to integrate pharmaceutical reforms with a Europe-wide policy strategy. This plan is essential for addressing current healthcare gaps and enhancing the quality of life for the 30 million EU citizens with rare diseases.

"As we move forward, EURORDIS-Rare Diseases Europe is committed to collaborating with MEPs to ensure the pharmaceutical legislative revisions embody the aspirations and requirements of the rare disease community. Our mission is clear: to ensure this legislative update stands as a testament to the EU's commitment to every person affected by a rare disease."

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting people, families and rare disease groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and services.

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