Media Statement

EURORDIS welcomes European Parliament plenary vote on pharmaceutical package

***9 April 2024, Brussels* – EURORDIS has welcomed the latest European Parliament plenary vote on the proposed reforms to the EU's general pharmaceutical legislation, which include proposed updates to regulations on orphan medicinal products and paediatric medicines.**

In the latest plenary vote, Members of the European Parliament (MEPs) at large voted in favour of the compromise amendments passed last month by the Parliament's Committee on the Environment, Public Health, and Food Safety (ENVI) in March 2024, which EURORDIS had lauded as a 'meaningful step' forward in the ongoing efforts to bridge the gap between rapid scientific progress and patient care.

Responding to the results of the European Parliament's plenary vote on the proposed reforms, **Valentina Bottarelli**, Public Affairs Director at EURORDIS, said:

> "Today's plenary vote by the European Parliament on pharmaceutical reforms marks a significant stride forward for the 30 million Europeans living with rare diseases and their families. Against the backdrop of 94% of rare diseases still lacking a dedicated treatment, we welcome the genuine political will that has been demonstrated to improve treatment development and access.
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> "We support the MEPs' approval of crucial proposals, such as introducing progressive market exclusivity for orphan drugs, refining the 'significant benefit' criteria, and clearer 'High Unmet Medical Needs' classification. These changes, along with enhancing the PRIME scheme and ensuring patient participation in EMA consultations, represent not just progress but the result of our community's advocacy to close the gap between fast-paced scientific discoveries and patient care.
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> "The commitment to an EU policy framework for rare diseases, endorsed by the European Parliament position, aligns with our longstanding call for a European Action Plan for Rare Diseases. Importantly, this endorsement builds on an already strong and broad political consensus, spanning EU institutions and Member States, on the urgent need for such an Action Plan.
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> "As we progress to the next stages of the proposed reform, Member States should acknowledge and build upon the Parliament's recommendations. Additionally, the Council should seize the opportunity that remains to further refine the legislation by incorporating an 'Orphan Drug Development Plan' in the legislation, to help navigating the journey of more and better rare disease treatments to patients."

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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