Question for written answer E-000886/2025
to the Commission
Rule 144
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Subject: Action plan on rare diseases

On International Rare Disease Day, 28 February 2025, we will demonstrate our solidarity with approximately 27 to 36 million people living with a rare disease in the EU. The inclusion of these individuals in our societies is vital, but despite commendable initiatives, such as the European Reference Networks, they still face health and social inequities.

Market and patient access to orphan medicinal products or treatments is a widely recognised issue of near-unpayability for individuals and Member States' healthcare systems. Research into and development of orphan therapies must remain a priority of European pharmaceutical policy. However, the increasing costs of orphan medicines on Member States' healthcare budgets may challenge solidarity with rare disease patients.

1. Does the Commission agree with the identified opportunities and gaps in research and knowledge, diagnosis and codification, market failure, market access, patient access and high prices?

2. Will the Commission propose an overarching action plan on rare diseases that addresses remaining opportunities and creates a European policy framework to support the revision of national plans for rare diseases?

3. Does the Commission intend to create a European financial solidarity instrument to improve access to rare disease treatments?

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