

**Question for oral answer O-000068/2021
to the Commission**

Rule 136

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on behalf of the Renew Group

Subject: EU action plan on rare diseases

While policies over the last two decades have brought tremendous progress for patients living with a rare disease, most of them are now outdated.

The 30 million people living with a rare disease in the EU still face a high level of unmet needs. They wait five years on average for a diagnosis and, once diagnosed, treatments are only available for 6 % of known rare diseases. Patients with rare diseases are also disproportionately affected by psychological, financial and social burdens.

Since the last overarching EU policy on rare diseases was introduced in 2009, technological and scientific advances have improved the way we diagnose and treat rare diseases and care for affected patients, making policies outdated, if they have not already expired.

The EU-funded Rare 2030 foresight study of February 2021 on the future of rare disease policy calls for a new policy framework for rare diseases. Additionally, a 2019 report by the Court of Auditors recommended that the Commission assess the EU's rare disease strategy and whether it needs to be 'updated, adapted or replaced by 2023'. This call was widely echoed by Parliament in its resolution of 10 July 2020 on the EU's public health strategy post-COVID-19.

Against this background:

1. What plan does the Commission have to implement the recommendations of the Rare 2030 foresight study?
2. When does it intend to conduct the review recommended by the European Court of Auditors in its 2019 report?
3. Will it introduce an EU action plan for rare diseases by 2023 in the form of a comprehensive plan with measures and targets, in order to leave no one living with a rare disease behind?

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Lapses: 19.1.2022