

**Question for written answer E-004819/2025/rev.1
to the Commission**
Rule 144
Gerald Hauser (PfE)

Subject: Cost of endless negotiations on rare diseases

In the EU, there are more than 30 million people with rare diseases and around 100 million people with disabilities. The European Parliament has been discussing rare diseases and the situation of persons with disabilities for years, including the demand for an EU action plan on rare diseases and the implementation of the Strategy for the Rights of Persons with Disabilities 2021-2030. To date, however, there have been endless meetings and a great deal of organisational effort – taking up a lot of time and incurring considerable costs – without any results.

1. How does the Commission justify the significant organisational costs and time spent when, despite years of deliberations, hardly any concrete progress has been made?
2. What costs have been incurred to date as a result of the meetings and the various events on rare diseases, broken down by year? Please provide estimates in the absence of precise figures.
3. How will the Commission ensure in future that financial and human resources are used more efficiently and are not wasted through endless meetings?

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