

Question for written answer E-002187/2025
to the Commission
Rule 144
Dimitris Tsiodras (PPE)

Subject: Improving access to diagnosis and treatment for people with rare diseases

The number of people with rare diseases in the EU is estimated at 30 million, while the number of rare diseases is estimated at 6-8000. Diagnosis can take more than five years, while many people never receive a timely or adequate diagnosis. At the same time, the high cost of treatments, unequal access to treatments and the limited availability and geographical dispersion of specialists and centres of expertise mean that people with rare diseases have difficulty accessing care and support.

In view of this:

1. Following the adoption of the resolution on rare diseases by the World Health Assembly, will the Commission draw up an action plan on rare diseases with a view to implementing the provisions of the resolution?
2. How will the Commission contribute to improving timely access of patients with rare and undiagnosed diseases to diagnosis, care, treatment and support services?
3. Following successful national prevention programmes for other diseases, such as Greece's 'Prolamvano', how does the Commission intend to provide technical support for the strengthening and implementation of national policies on rare diseases and how will it enhance collaboration, networking and knowledge exchange between specialist healthcare providers to improve expertise in the field of diagnosis?

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