EN
E-002187/2025
Answer given by Mr Várhelyi
on behalf of the European Commission
(20.8.2025)

1. The Commission is already supporting Member States in addressing the recent World Health Organization's resolution on rare diseases (RD)[1] by means of a strong EU framework based on a Council Recommendation[2] and a Commission Communication[3] on RD. The Joint Action JARDIN[4] on integration of the European Reference Networks (ERNs) for RDs into national healthcare systems will provide an overview of best practices, the RD landscape in the EU and inform any decisions on a possible EU action plan. Until then, EU actions on RD will continue in their current form.

2. The 24 ERNs support Member States in pooling RD resources and expertise, with specialists discussing patients' cases across borders to find the best diagnosis and treatments, with expertise travelling and not the patients. Over 3,500 specialist panels have been conducted via an EU-funded Clinical Portal Management System (CPMS)[5]. The Commission also supports health systems by funding RD research and innovation, with more than EUR 120 million under EU4Health Programme and more than EUR 640 million in the first two years of Horizon Europe[6]. It funds actions such as collaborative research projects for RD therapies[7] or diagnostics, public-private projects[8] and the European Partnership on RD ERDERA[9], co-funded with Member States.

3. Both JARDIN and ERDERA are supporting national policies on RD to identify, share and implement best practices. ERDERA encourages the establishment of 'National Mirror Groups' for RD policies in its 37 participating countries. JARDIN has established an ERN-overarching expert panel for undiagnosed cases unsolvable at national level, requiring interdisciplinary input. It will be incorporated into everyday activities of ERNs, including experts' use of the CPMS.

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[1] https://apps.who.int/gb/ebwha/pdf_files/EB156/B156_(15)-en.pdf.
[2] Council Recommendation of 8 June 2009 on an action in the field of rare diseases OJ C 151, 3.7.2009, p. 7–10.
[3] Communication from the Commission of 11 November 2008 on Rare Diseases https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:52008DC0679.
[4] Joint Action on the integration of ERNs into national health systems (with EUR 15 million of EU funding), more information: https://jardin-ern.eu/.
[5] https://ern-euro-nmd.eu/clinical-patient-management-system-cpms/.
[6] https://research-and-innovation.ec.europa.eu/research-area/health/rare-diseases_en.
[7] https://cordis.europa.eu/programme/id/HORIZON_HORIZON-HLTH-2022-DISEASE-06-04-two-stage/en.
[8] Such as RealiseD under the Innovative Health Initiative https://cordis.europa.eu/project/id/101165912.
[9] European Rare Diseases Research Alliance (with up to EUR 150 Million of EU funding), https://erdera.org/ ; https://cordis.europa.eu/project/id/101156595.