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Answer given by Mr Várhelyi
on behalf of the European Commission
(18.2.2026)

In regard to the Strategy for the rights of persons with disabilities 2021-2030¹, the Commission announced that the Strategy will be updated in the second quarter of 2026. In regard to an EU action plan on rare diseases, the Commission considers that the current EU legal and policy framework for rare diseases is adequate and allows the Commission and Member States to develop the necessary actions as needed.

The only meetings regarding rare diseases organised by the Commission are those set out under Directive 2011/24/EU on the application of patients' rights in cross-border healthcare² for the governance of the European Reference Networks (ERNs). These include two annual meetings of the ERN Board of Member States and 24 ERN Coordinators. The reimbursement costs for on-site meetings follow the regular Commission's rules. The ERNs enable patients with rare diseases to access highly specialised expertise across Europe without the need to travel. As the integration of the outcomes and lessons learned from the European Reference Networks into national health systems becomes increasingly important, 12 workshops on cross border healthcare and the ERNs were co-organised with the 16 national competent authorities of the Member States that were involved, as some workshops were organised jointly by two Member States in a border region. The cost to organise the workshops and communication material in 21 official EU languages amounted to EUR 500 000.

The Commission is committed to sound financial management of EU resources. Meetings are organised only where they add clear value to policy development or its implementation. Whenever possible, discussions are integrated into existing governance structures and expert groups to ensure synergies and to avoid any duplication. The Commission also promotes the systematic use of hybrid and online formats, which has significantly reduced costs while allowing broad and inclusive participation.

¹ https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/disability/union-equality-strategy-rights-persons-disabilities-2021-2030_en.

² <https://eur-lex.europa.eu/eli/dir/2011/24/oj/eng>.