

(English version)

**Question for written answer E-000537/25
to the Commission**

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(5 February 2025)

Subject: Rare diseases and paediatric transplants

Rare diseases often require complex therapeutic procedures, such as paediatric transplants, which are essential for the treatment of many patients. In 2023 alone, more than 1 500 paediatric transplants were performed in Europe. However, these procedures are not always explicitly recognised as part of the treatment for rare diseases, making it difficult to properly allocate resources and to include them in the European Reference Networks.

Furthermore, the mobility of healthcare professionals is key to ensuring excellence in these procedures. In particular, doctors with years of experience need access to training stays in reference centres in other countries to acquire advanced training and apply best practices in their home countries.

In this context:

1. Does the Commission plan to adopt measures to recognise ‘complex therapeutic procedures’ as part of the treatment of rare diseases, ensuring the inclusion of the centres and professionals carrying out these procedures in the European Reference Networks?
2. What initiatives will the Commission promote to facilitate the mobility of healthcare professionals, allowing them to train in specialised centres and fostering knowledge exchange in advanced paediatric care?

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Answer given by Mr Várhelyi on behalf of the European Commission
(2 April 2025)

1. The definition of health policy and the organisation and delivery of health services and medical care is a Member State competence. EU actions in the field of rare diseases complement national policies and aim to encourage cooperation across Member States. Therefore, the Commission does not plan to adopt any measure to recognise ‘complex therapeutic procedures’ as part of the treatment of rare diseases. However, the European Reference Network (ERN) TransplantChild⁽¹⁾, one of the 24 ERNs funded by the EU, has been working since 2017 on paediatric transplantation, striving to make the latest techniques and medical, pharmacological and therapeutic advances available, while facilitating the dissemination of harmonised clinical practice guidelines and the development of personalised paediatric transplantation medicine.

2. The Commission previously funded a project that supported the mobility of ERN healthcare professionals, allowing them to follow training sessions in specialised ERN centres. Under the current grants for the ERNs (2023-2027), worth EUR 77.4 million (amounting to around EUR 3.25 million per ERN), training and education activities are specifically included, organised and implemented by each ERN, including the ERN TransplantChild.

⁽¹⁾ <https://transplantchild.eu/>