

EN
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Answer given by Mr Várhelyi
on behalf of the European Commission
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Foetal alcohol spectrum disorder is classified as rare disease (ORPHA 1915). Since 2017, the Commission has been funding the European Reference Networks for Rare Diseases (ERNs), which enable specialists in Europe to discuss cases of patients affected by rare, low-prevalence and complex diseases, providing advice on the most appropriate diagnosis and the best treatment available. Foetal alcohol spectrum disorder in particular is covered by the ERN for Rare Malformation Syndromes and Rare Intellectual and Neurodevelopmental Disorders (ITHACA).

The Strategy for the Rights of Persons with Disabilities 2021-2023 further supports self-determination, autonomy and participation. It covers persons with different kinds of disabilities equally. Rare diseases often lead to disabilities and thus the Strategy in its health area focuses on fostering research and innovation on rare diseases. The Pharma Package also intends to make orphan drugs against rare diseases more accessible¹.

The Commission is currently implementing the current actions of the Strategy. On different occasions, including the meetings of the Disability Platform, it discusses progress on implementation, which can help define new needs to be integrated into the Strategy and feed into future policy measures.

¹ https://commission.europa.eu/document/ab0bcea9-6b3a-48c1-875c-1cc687fba6d0_en.