

**Question for written answer E-003363/2020
to the Commission**

Rule 138

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Subject: Huntington's disease – the impact of COVID-19 on delivery of care

COVID-19 has placed unprecedented strain on European health systems and shed light on the need for more investment and better infrastructure. Rare diseases affect over 400 million people worldwide – more than cancer – including 30 million in Europe. Their unique, complex nature poses significant challenges for health and social care systems.

People with rare diseases such as Huntington's disease experience significant delays in diagnosis, fragmented care and lack of access to treatment. This impacts Huntington's disease patients, their families and carers, and health-related quality of life, on account of the high levels of support required to deal with increased disability (motor, cognitive and behavioural disturbances) and loss of independence. COVID-19 is exacerbating these challenges.

On the issue of Huntington's disease, how is the Commission supporting national healthcare systems to:

1. improve access to the appropriate rare disease infrastructure, including high-quality care services, particularly given the new demand on healthcare systems as a result of COVID-19?
2. ensure that all individuals at risk of genetic disorders are able to access genetic counselling, regardless of whether they go on to have genetic screening?

Based on the lessons learnt from COVID-19, does the Commission believe that it should broaden the scope of its areas of competence in order to support Member States with rare disease infrastructure needs?