Question for written answer E-004156/2020 to the Commission Rule 138 Tomislav Sokol (PPE)

Subject: Providing opportunities to people with rare diseases

Scientific research has concluded that there are over 6 000 clinically defined rare diseases in the world, of which 72% are genetic, with 70% of these developing in childhood. In absolute terms, it is estimated that approximately 300 million people live with some form of rare disease, accounting for 4% of the world's population. ¹ They face various problems, such as inequalities in employment, social exclusion and various prejudices that make their lives more difficult. In light of this:

- 1. What steps is the Commission taking to provide people with rare diseases with equal opportunities in employment, social protection and social inclusion, especially during COVID-19?
- 2. How can the Commission give people suffering from a rare disease access to innovative treatments?

¹ Source: 'Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database', https://www.nature.com/articles/s41431-019-0508-0, pregledano 29.06.2020.