Question for written answer E-002554/2020
to the Commission
Rule 138
Stelios Kympouropoulos, Chrysoval Zacharopoulou, Isabel Carvalhais, Ivan Štefanec, José
Manuel Fernandes, Milan Brglez, Katefina Konecná, Miriam Dalli, Giorgos Georgiou, Alex
Agius Saliba, Marianne Vind, Cindy Franssen, Radka Maxová, Katrin Langensiepen, Brando
Benifei, Tanja Fajon, Anna-Michelle Asimakopoulou, Marisa Matias, Ádám Kósa, Josianne
Cutajar, Nils Torvalds, Atidzhe Alieva-Veli, Pascal Durand, José Gusmão, Loucas Fourias

Subject: Rare diseases and employability

There are about 7 000 rare diseases (80 % with a genetic component) in total, which collectively
affect more people than cancer. The number of people with rare diseases is estimated at over 400
million worldwide.

In the EU, rare diseases affect almost 30 million citizens. They are often chronic and progressive, with
a devastating impact on a person’s well-being, quality of life and ability to perform day-to-day
activities. Most people living with a rare disease have mobility problems and have to contend with
profound inequalities in relation to employability and social inclusion. The Commission has committed
to tackling the problems related to rare diseases by reducing disparities and inequalities in patient
access to diagnosis, information and care.

How does the Commission guarantee equal and early access to effective healthcare services for
people living with rare diseases, including advanced management and care, across all patient
populations affected in all Member States?

What measures has the Commission taken to strengthen collaboration with all health and social
stakeholders to achieve improved outcomes for rare disease patients in all Member States?

What steps is the Commission taking to ensure that persons with disabilities who have mobility
problems caused by rare diseases have equal access to employment opportunities, social protection
and inclusion measures across the Member States?