

**Question for written answer E-000365/2022
to the Commission**

Rule 138

István Ujhelyi (S&D), **Hilde Vautmans** (Renew), **Stelios Kympouropoulos** (PPE), **Maria da Graça Carvalho** (PPE), **Radan Kanev** (PPE), **Josianne Cutajar** (S&D), **Brando Benifei** (S&D), **Sara Cerdas** (S&D), **Magdalena Adamowicz** (PPE), **Javier Nart** (Renew), **Ioannis Lagos** (NI), **Nathalie Colin-Oesterlé** (PPE), **Patrizia Toia** (S&D), **José Gusmão** (The Left), **Radka Maxová** (S&D), **Loucas Foulas** (PPE), **Gianna Gancia** (ID), **Tudor Ciuhodaru** (S&D), **César Luena** (S&D), **Ioan-Rareş Bogdan** (PPE), **Cristian-Silviu Buşoi** (PPE), **Liudas Mažylis** (PPE), **Rosanna Conte** (ID), **Juozas Olekas** (S&D), **Petar Vitanov** (S&D), **Katrin Langensiepen** (Verts/ALE), **Ewa Kopacz** (PPE)

Subject: Awareness-raising of the need for an action plan for rare diseases and the need to tackle health inequalities in the EU

In the EU, over 30 million people live with a debilitating and chronic rare disease such as sickle cell disease. Those living with rare diseases face multiple and complex challenges. Many of these patients experience significant health inequalities and are stigmatised. The COVID-19 pandemic has exacerbated these inequalities, with 84 % of people living with a rare disease reporting a direct experience of disruption of care.

Among those rare diseases is sickle cell disease (SCD), a rare, inherited disorder affecting more than 52 000 people in Europe. SCD is the most prevalent genetic disease in Europe, and SCD patients are a case in point for EU and national policymakers to focus on where policy change can help address some of the unmet needs of this patient community.

With the revision of the Orphan Medicinal Products (OMP) Regulation and considering the need to address health inequalities and the unmet needs of people living with rare diseases:

1. Does the Commission intend to include the introduction of universal newborn screening in the revision of the OMP Regulation?
2. Will it develop an action plan for rare diseases by 2023, including EU guidelines and training for healthcare professionals, so as not to leave behind anyone living with a rare disease?

Supporters¹

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