
Rare diseases: Kyriakides (Commissioner), “for more than 20 years, the EU has made the work in this area a priority”

There are 36 million people in the EU suffering from a rare disease. Since at national level “resources and expertise to treat these diseases are often scarce”, the “added value of EU action” is “undisputable”, European Commissioner for Health, Stella Kyriakides, said today, ahead of World Rare Disease Day, adding that only cooperation ensures “that everyone receives timely diagnosis, as well as affordable treatment and care”. The 24 European Reference Networks (ERNs) that today bring together experts from over 1,600 centres in 382 hospitals are “a true success story of European cooperation”, according to Kyriakides. In the coming years, the Commissioner announced, the EU will be investing more than €77 million to consolidate and improve these networks, and €18 million to better integrate them into the national healthcare systems of EU countries (as well as of Norway and Ukraine). Moreover, under the Horizon Europe programme, €100 million will go to developing diagnostics and treatments under a new European Partnership on Rare Diseases. Also on the table is a reform of the EU pharmaceutical legislation to steer pharmaceutical investment and focus on underserved areas. Finally, the European Health Data Space will help research, innovation, and policymaking. According to Commissioner Kyriakides: “For more than 20 years, the EU has made the work in this area a priority. By putting patients at the centre, we have become a pioneer in the fight against rare diseases”.

Sarah Numico