



Statement by Commissioner Kyriakides on the World Rare Disease Day - Stronger together

Brussels, 28 February 2024

"For up to 36 million people across the EU today, living with a rare disease is a daily reality. Most of them have no cure, and this causes fear and frustration. At national level, resources and expertise to treat these diseases are often scarce, making the added value of EU action undisputable.

In a strong European Health Union, nobody should be left behind, no matter where they live, no matter their disease. Therefore, we need strong EU cooperation to ensure that everyone receives timely diagnosis, as well as affordable treatment and care.

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.

Our 24 European Reference Networks (ERNs) that today unite rare disease doctors and specialised healthcare providers across the EU are a true success story of European cooperation. They ensure that information travels so that patients do not have to, and involve over 1,600 specialised centres in 382 hospitals all over the EU and Norway.

In the coming years, the EU will be investing more than €77 million to consolidate and improve these networks. To better integrate them in the national healthcare systems, we are funding a new Joint Action with over €18 million over the next three years. In addition to all EU Member States and Norway, this action will also include Ukraine as part of our commitment to deepen ties in the area of health. In addition, we are providing financial support under the Horizon Europe programme, which includes €100 million for developing diagnostics and treatments under a new European Partnership on Rare Diseases.

Looking ahead, as part of the pillars of the European Health Union, the reform of the EU pharmaceutical legislation aims to steer pharmaceutical investment into medicines for rare diseases and focus on underserved areas through targeted incentives and regulatory support. The reform will also help innovation to reach patients across the EU. With the European Health Data Space digital health data will become more available for research, innovation and policymaking, to benefit also patients with rare diseases.

The pooling of resources and joint actions at EU level is particularly important for rare diseases. We need to collectively continue the work to improve lives - on World Rare Disease Day and every day. Together we are stronger."

[Factsheet on EU actions on rare diseases](#)

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