

Media statement

EURORDIS welcomes MEPs' proposal of amendments on health to EU Treaties

22 November, Brussels – EURORDIS-Rare Diseases Europe has welcomed the European Parliament's latest vote on proposed amendments to the EU Treaties. Among the amendments endorsed by Members of the European Parliament (MEPs) are amendments to the EU Treaties that would expand the EU's role in advancing policies aimed at improving the health of EU citizens.

Responding to the vote, **Valentina Bottarelli**, Public Affairs Director and Head of European Advocacy at EURORDIS, said:

"This vote recognises the need for expanding the EU's competences to further encompass health policy areas, offering hope for the improved wellbeing for all EU citizens, especially those with rare conditions. Rare disease healthcare is a policy area which perfectly exemplifies where EU-level actions can provide high added value to Member States. The limited size of specific rare disease patient groups often leads to a lack of clinical expertise, research, and treatments for the 30 million people living with a rare condition across Europe. The EU's pooling of resources and the creation of a unified policy framework can, and does, effectively address these challenges.

"A coordinated and collaborative EU approach in health policy is vital, particularly with regard to rare diseases. By establishing a shared competence on public health matters, in particular concerning the protection and improvement of human health – especially on cross-border health threats (new suggestion for Article 4 TFEU) and a specific focus on rare diseases for the supporting competences (new suggestion for Article 168 TFEU) – the EU stands to achieve far-reaching health objectives relating to more effective, equitable healthcare solutions that Member States would struggle to achieve by themselves.

"We therefore welcome the proposed amendment to the Treaties which mentions rare diseases explicitly and would mandate that the European Commission monitors and coordinates EU citizens' access to diagnosis, information, and treatment.

"The COVID-19 pandemic underscored the need for more integrated EU health policies and demonstrated the EU can be capable of a unified, efficient response to global health crises.

"Furthermore, greater EU involvement in health policy might have historically accelerated the development of vital policies and pieces of legislation relating to rare disease healthcare.

"The favourable stances of the Spanish Presidency and the European Commission on MEPs' proposed health amendments to the Treaties are encouraging signs. They suggest a strong likelihood of the



adoption of health-focused amendments to the EU Treaties – a step forward that we eagerly anticipate."

About EURORDIS-Rare Diseases Europe

<u>EURORDIS-Rare Diseases Europe</u> is a unique, non-profit alliance of over 1,000 rare disease organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting people, families and rare disease groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and services.

Contact

Julien Poulain
Communications Manager
EURORDIS-Rare Diseases Europe
Julien.poulain@eurordis.org
+33 6 42 98 14 32

