

Press release

EURORDIS-Rare Diseases Europe welcomes the agreement on the Proposal for a Regulation on European Cooperation in Health Technology Assessment

Paris, 22 June 2021 – The European rare disease community praises the informal agreement between the European Commission, Parliament, and Council on the Proposal for a Regulation on European Cooperation in Health Technology Assessment (HTA).

EURORDIS-Rare Diseases Europe congratulates the efforts made by the co-legislators, which helped to dramatically improve the final text and reach a balanced compromise. The Regulation, first proposed in 2018, is a logical result of over 20 years of project-based cooperation between the European Union Member States. With such Regulation in place, patients can expect their national authorities to provide more robust, transparent, and complete information about new medicines, devices, and diagnostics, while benefiting from the expertise of all 27 EU countries. This enhanced and sustainable collaboration between Member States should produce more cohesive scientific advice and high-quality HTA reports across Europe, laying the course for needs-led and patient-centred health policies.

"The HTA Regulation, as part of the European Pharmaceutical Strategy, is a crucial and necessary step to strengthen our health systems and make them future-proof," – said Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe. "Effective European cooperation in HTA with joint scientific consultations and joint clinical assessments is the only way forward to get a more consistent health technology assessment across the EU, which is vital to accelerate access to the treatments patients need the most."

EURORDIS stands ready to offer its expertise in developing inclusive, transparent, and evidence-based Health Technology Assessment and calls on the European Union policy makers to fully commit to the formal adoption and implementation of the HTA Regulation in the near future.

###

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 962 rare disease patient organisations from 73 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

By connecting patients, families and patient 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 patient services. Follow @eurordis or see the EURORDIS Facebook page. For more information, visit eurordis.org.

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

Press contact

Stanislav Ostapenko
Communications Manager
EURORDIS-Rare Diseases Europe
stanislav.ostapenko@eurordis.org
+33 1 56 53 52 61