



## Media Statement

# EURORDIS: EU<sub>4</sub>Health must recognise added value of EU action on rare diseases

**19 June 2024, Brussels** – Following the European Commission’s [EU<sub>4</sub>Health Stakeholders’ Conference](#), EURORDIS-Rare Diseases Europe urges the Commission to recognise the key health needs of the rare disease populations in the EU<sub>4</sub>Health 2025 Work Programme and the necessity of continued EU action in an area of high additionality and EU added value.

EURORDIS welcomes the European Commission’s efforts prepare a meaningful annual work programme of EU<sub>4</sub>Health despite the recent budget cut of the programme by one fifth. We also praise the Commission’s efforts to collaborate with stakeholders to refine the strategy of the EU<sub>4</sub>Health and reflect on the key health needs of the European population with stakeholders.

Responding to the European Commission’s overview of the EU<sub>4</sub>Health consultation delivered at the Stakeholders’ Conference, **Valentina Bottarelli**, Public Affairs Director at EURORDIS, said:

“We are delighted to see the focus on the added value of EU actions in this phase of budget redeployment. Rare diseases have been an EU public health priority for decades due to the significant added value of EU action in a field where no country can succeed alone.

“As we move towards consolidation of the 2025 EU<sub>4</sub>Health Work Programme, we urge the European Commission to maintain this direction and address the unmet needs of the rare disease community in the coming weeks.

“This direction is crucial for fostering collaboration, enhancing preparedness for health threats, and addressing the needs of both people with rare diseases and the broader EU population who will benefit from a stronger European Health Union. The future of the European Health Union depends on supporting its most vulnerable citizens, including the 30 million people in Europe living with a rare disease and their families. The time for action is now.”

EURORDIS’ submission to the *European Commission’s Targeted Consultation on the 2025 EU<sub>4</sub>Health Annual Work Programme* includes recommendations such as:

- Supporting the adoption of a *European Action Plan for Rare Diseases* by creating a scoping working group to set out common objectives and indicators for national rare disease plans.
- Standardising newborn screening programmes through a joint action promoting cross-country collaboration and the sharing of best practices.

- Continuing support for the European Reference Networks and establishing a European system to centralise the commissioning and delivery of highly specialised healthcare services for very small patient populations.
- Building a Single Market for rare disease therapies with coordinated EU policies and joint procurement to ensure equitable access to treatments.
- Fully adopting digital health technologies, such as Electronic Health Records and telemedicine.
- Developing a '*Mental Health Toolkit*' for vulnerable populations.

The rare disease community strongly supports EURORDIS' priorities and recommendations. Last month, hundreds of advocates at the [12th European Conference on Rare Diseases and Orphan Products \(ECRD 2024\)](#) endorsed recommendations in an Open Letter which align with those included in EURORDIS' submission to the EU4Health consultation. This Open Letter [remains open to signatures](#).

## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) 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

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