



## Press Release

# Health innovation among proposals in Draghi's competitiveness report

**9 September 2024, Brussels** – EURORDIS–Rare Diseases Europe welcomes the publication of Mario Draghi's report on EU competitiveness, presented to the European Commission, to which our organisation was invited to contribute. The report addresses several key areas crucial to the rare disease community, particularly in pharmaceutical innovation, healthcare access, and research.

As the organisation representing people living with a rare disease across Europe, EURORDIS is both pleased and grateful to have been consulted during the drafting process, ensuring that the voices of those impacted by rare diseases were heard and considered throughout the report's development.

Presenting his report, former Italian Prime Minister and European Central Bank President Mario Draghi emphasised the need for “radical change” in the EU, citing the fierce competition the bloc faces from both China and the United States.

Responding to the report, **Virginie Bros-Facer**, Chief Executive of EURORDIS, stated:

“We are grateful for the focus the Draghi report places on healthcare and innovation, which are of critical importance to the rare disease community. With over 30 million people in Europe impacted, treatments exist for less than 6% of known conditions, and patients face an average five-year wait for a diagnosis. It is vital for the EU to not only strengthen but also revitalise Europe’s healthcare, medical technology, and pharmaceutical sectors. We hope that the recommendations in this report could lay the foundations for a stronger, more resilient health policy framework – one that fosters innovation, ensures equity and guarantees long-term sustainability in meeting the needs of rare disease patients.

“We are pleased to see the report highlight joint procurement and the need to step up cross-country initiatives for joint pricing and reimbursement negotiations for specific medicines, both of which represent important steps toward ensuring rare disease patients have coordinated, cost-effective access to the treatments they urgently need. We also fully support the report's vision of positioning Europe as a global leader in innovation, fostering a robust environment for research and development. This must include bolstering the rare disease ecosystem and critical infrastructures like the European Reference Networks, which connect scarce expertise across borders.

“Additionally, the report’s emphasis on strengthening the European Health Data Space (EHDS), promoting multi-country clinical trials, and enhancing the use of artificial intelligence in healthcare presents a real opportunity to accelerate the development of orphan medicines. These measures, alongside increased investment in research and innovation, particularly in collaboration with the

European Reference Networks (ERNs), could transform the landscape for rare disease patients across Europe, providing them with faster access to diagnosis and new therapies.

“As the new European Commission takes office, we strongly urge policymakers to keep health and research, particularly for rare diseases, at the forefront of their agenda. While we are concerned about proposed cuts to the EU4Health programme and the lack of updates on future health strategies, this report presents a timely opportunity to address the challenges faced by our community and foster collaboration among Member States, ensuring that no patient is left behind.”

EURORDIS will conduct a more comprehensive review of the report in the coming days to evaluate how well it meets the needs of rare disease patients

## 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

**Julien Poulain**

Communications Manager

EURORDIS-Rare Diseases Europe

[Julien.poulain@eurordis.org](mailto:Julien.poulain@eurordis.org)

+33 6 42 98 14 32