

Media Statement

EURORDIS welcomes EPSCO call for inclusion of health priorities in EU Strategic Agenda

21 June 2024, Brussels – EURORDIS-Rare Diseases Europe welcomes the unanimous conclusions reached by the 27 health ministers (<u>Council conclusions on the Future of the European Health Union:</u> <u>A Europe that cares, prepares and protects</u>) at today's Employment, Social Policy, Health, and Consumer Affairs (EPSCO) Council meeting, urging national heads of government in the European Council to prioritise health in the upcoming 2024-29 EU Strategic Agenda.

Notably, the EPSCO Council's conclusions highlight that "solidarity is a fundamental principle of the European Union and a pillar on which the Health Union should be built" and urgent Member States to "promote solidarity in the field of health."

The conclusions also stress the "urgent need to continue to build upon and improve the European Health Union in light of the systemic challenges our health systems are facing today."

Importantly, the 27 health ministers have called on Member State leaders and the European Commission to support the implementation of effective policies in the area of non-communicable diseases, "including as strands, action plans on health determinants, cancer, cardiovascular diseases, chronic respiratory diseases, diabetes, mental health and neurological disorders, and rare diseases." A proposed action plan for rare diseases, in particular, would be a crucial step towards ensuring that the 30 million people living with a rare disease and their families are not overlooked in the development of a European Health Union.

Commenting on the developments at today's EPSCO Council meeting, **Valentina Bottarelli**, Public Affairs Director at EURORDIS, said:

"We are greatly pleased that the 27 health ministers have unanimously called for the European Council to prioritise health in the next EU Strategic Agenda and establish a true European Health Union over the new five-year mandate, including a European plan for rare diseases. EURORDIS, alongside the European Parliament, the European Economic and Social Committee (EESC), and the European Court of Auditors, has long called on the European Commission to deliver a dedicated European action plan on rare diseases. This overdue action plan in an area of high EU added value is vital to addressing the unmet needs of the 30 million people living with a rare disease in the EU, along with their families and caregivers.

"We are also encouraged to learn that the approaching Hungarian Presidency of the Council of the EU will prioritise rare diseases and host a high-level conference on the topic in Budapest with the European Economic and Social Committee (EESC). This underscores the importance of keeping rare diseases on the EU's political agenda as we enter a new five-year mandate. The Hungarian





Presidency's prioritisation of rare diseases also underscores the ongoing recognition by consecutive Council presidencies of the value of EU-level action in rare disease policymaking, building on the efforts of the preceding French, Czech, Spanish, and Belgian presidencies.

"In light of the EPSCO Council's conclusions and Belgian Health Minister Frank Vandenbroucke's assertion that a European Health Union is crucial for the survival of national health systems, it is imperative that the European Council prioritises health in its upcoming Strategic Agenda. The responsibility now lies with the European Council and the next European Commission to act on this critical imperative."

At the <u>12th European Conference on Rare Diseases and Orphan Products (ECRD 2024</u>), EURORDIS launched an Open Letter for delivery to the next European Commission, already signed by two thousand supporters and counting. This letter advocates for a European Action Plan for Rare Diseases and calls for enhanced EU policies on diagnostics, treatment access, cross-border healthcare, mental health support, research funding, and national plans. <u>The Open Letter remains open for additional signatures</u> from the rare disease community before it is handed over to the newly elected European Commission in the autumn.

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.

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