



## Media Statement

### Greater focus needed on rare diseases in EU health mandate

**17 September 2024, Brussels** – European Commission President Ursula von der Leyen has today announced her team of nominated European Commissioners and the policy portfolios they may oversee for the next five years. While EURORDIS welcomes the focus on key health issues, we emphasise the need for greater attention to rare diseases, urging the Commission to ensure this critical area is prioritised in the upcoming mandate.

Hungarian politician **Olivér Várhelyi** has been nominated as Commissioner for Health and Animal Welfare, with a mandate to tackle key issues including medicine shortages, enhancing innovation and competitiveness in Europe's pharmaceutical sector, and advancing the European Health Union.

Várhelyi's mission letter from von der Leyen also details the responsibilities of collaborating with EU institutions and Member States to strengthen healthcare systems, ensure access to medicines, and address the health concerns of European citizens.

The nominees to Commissioner portfolios will not be installed in their new roles until they successfully pass a confirmation vote in the European Parliament. However, EURORDIS is putting forward its position now to ensure that rare diseases are given priority in the new health agenda.

In response to the mandate detailed by von der Leyen to Várhelyi, **Virginie Bros-Facer**, Chief Executive of EURORDIS, said:

"We welcome the references to the Enrico Letta and Mario Draghi reports in the mission letter to the nominated health commissioner. Both reports advocate for concrete EU actions to develop treatments and improve access to them across Member States, with recommendations such as collaboration on pricing and reimbursement, as well as joint procurement. We also note that the mandate letter highlights the importance of ongoing work on the reform of EU pharmaceutical legislation, the completion of the European Health Data Space (EHDS), and the scaling up of genome sequencing capacities, which are crucial steps for our patients across Europe.

"However, we deeply regret that a renewed strategic approach to rare diseases was not explicitly mentioned in the mandate letter, despite repeated calls from stakeholders across the rare disease community and EU institutions. For people living with rare diseases, this would have been a strong signal that the EU is prioritising rare diseases as a core health issue for the upcoming mandate. We therefore hope that, as part of efforts to design common approaches like the EU Beating Cancer Plan, rare diseases will also be considered in line with the June 2024 (EPSCO) Council Conclusions on the Future of the European Health Union. We further hope that this will lead to the adoption of an EU Action Plan on Rare Diseases. By coordinating efforts across the EU, Member States can pool

resources, foster innovation, and support collaborative research, leading to more efficient diagnoses, better access to specialised treatments, and improved patient outcomes and social inclusion.”

In addition to Várhelyi’s nomination, other key appointments include **Ekaterina Zaharieva** as Commissioner for Startups, Research and Innovation, and **Hadja Lahbib** as Commissioner for Preparedness and Crisis Management; Equality.

We will closely follow these portfolios to ensure that rare disease policy is promoted and implemented across various areas in the coming mandate, in line with the recommendations in the Draghi report and mission letters.

## 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.

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