



Media Statement

EURORDIS congratulates new European Commissioners on their confirmation

27 November 2024, Strasbourg – EURORDIS-Rare Diseases Europe welcomes the new European Commissioners on their confirmation by the European Parliament.

We look forward to collaborating with them to address the needs of the 30 million people in Europe living with a rare disease.

Among the confirmed European Commissioners who will be particularly important to EU citizens impacted by rare diseases are:

- **Olivér Várhelyi**, Commissioner for Health and Animal Welfare. Mr Várhelyi's portfolio includes continuing negotiations around the revision of the EU general pharmaceutical legislation, proposing the Critical Medicines Act, advancing the implementation of the European Health Data Space, upscaling genome sequencing across the Union, strengthening European Reference Networks (ERNs) to improve care for those with rare and complex diseases, and – likely – reviewing the Medical Device Regulation.
- **Ekaterina Zaharieva**, Commissioner for Startups, Research and Innovation. Ms Zaharieva oversees the Horizon Europe Programme to advance research addressing societal challenges. Her objectives for the next five years will be to foster a conducive environment for startups by improving funding access and reducing administrative burdens, while driving digital innovation through AI and emerging technologies and enhancing Europe's research infrastructure.
- **Hadja Lahbib**, Commissioner for Preparedness, Crisis Management, and Equality. Ms Lahbib's expanded portfolio includes health preparedness, overseeing reproductive and sexual health issues, and strengthening the EU Civil Protection Mechanism for coordinated responses to health crises and natural disasters. In her equality mandate, she will promote policies to combat discrimination, foster inclusion, and implement the EU disability strategy.

Responding to the confirmation of **Olivér Várhelyi** in particular as the European Commissioner for Health, **Valentina Bottarelli**, Public Affairs Director at EURORDIS, said:

"We welcome the European Parliament's confirmation of Oliver Várhelyi as the new Health Commissioner, as the priorities that he had outlined during his confirmation hearing earlier this month should provide solutions to some of the key unmet needs of people living with rare diseases. His stated commitment to strengthening Europe's health systems, particularly by fostering resilience and innovation in the pharmaceutical and medical device sectors, reflects a clear understanding of the challenges ahead. His expressed plans to propose the Critical Medicines Act and the EU Biotech Act, advance the European Health Data Space, and explore joint procurement for orphan medicinal

products were all highlighted as his key ambitions during his hearing and would be vital steps toward addressing the unique challenges faced by rare disease patients across Europe.

“Commissioner Várhelyi’s focus on drug shortages, which he specifically addressed during the hearing, will be particularly important for the rare disease community, who are often disproportionately impacted by such shortages. Furthermore, his stated prioritisation of increasing the accessibility and availability of orphan and paediatric medical devices signals a much-needed response to the needs of patients and their families across Europe – this is important given the reality that one in three people with rare diseases has never received a treatment directly linked to their rare disease, because it does not exist, and 94% of rare diseases don’t have a specific treatment.

“We also welcome Commissioner Várhelyi’s strong emphasis on enhancing the European Reference Networks (ERNs), which he has aptly described as a ‘major success,’ along with his commitment to reducing barriers in cross-border healthcare. Given the limited knowledge and medical expertise on rare and complex diseases that often exist at the national level, fostering cross-border collaboration and pooling resources internationally is both logical and essential. We trust this support will be maintained when the EC will outline the long-term budget commitments of the EU.

“Finally, we are hopeful that Commissioner Várhelyi will advance a European Action Plan for Rare Diseases. This initiative has been endorsed by the European Parliament, the European Economic and Social Committee, and last June, the EU’s 27 health ministers in their Council Conclusion on future of the European Health Union. A goals-based Action Plan is urgently needed and long overdue, offering the most comprehensive strategy to address the unmet needs of Europe’s rare disease community.”

Responding to the confirmation of **Ekaterina Zaharieva** as the Commissioner for Startups, Research and Innovation, **Roseline Favresse**, EURORDIS Research Policy and Initiatives Director, said:

“During her confirmation hearing, Zaharieva was right to state her commitment to securing robust funding for the Horizon Europe programme, amid the threat of cuts to the programme. We also welcome the focus that she promised on simplifying processes for startups and SMEs, which would be critical steps toward fostering innovation in healthcare and medicine that can benefit the rare disease community. Her comments on retaining research talent within the EU and encouraging member state investment in research will have been encouraging to those from our rare disease community who want to see the creation of a stronger foundation for advancing diagnostics and therapies for rare diseases.

“We look forward to working closely with Commissioner Zaharieva to ensure that the unique needs of the rare disease community are prioritised in Europe’s research agenda.”

Finally, responding to the confirmation of **Hadja Lahbib** as the Commissioner for Preparedness, Crisis Management, and Equality, **Raquel Castro**, EURORDIS Director of Social Policy and Initiatives, said:

“The majority of people with rare diseases live with disabilities and face significant barriers to accessing their health, social, and independent living rights on an equal basis with others.

“Commissioner Lahbib’s portfolio offers a crucial opportunity to address some of these challenges by building more resilient healthcare systems, enhancing the EU’s capacity to respond to health crises, and advancing disability rights.

“As her mandate begins, we call on the Commissioner to ensure that the European Strategy for the Rights of Persons with Disabilities is updated with ambitious actions for its next phase. We also urge her to prioritise supporting Member States in strengthening disability assessment systems, ensuring people with rare diseases are not left behind due to inadequate recognition of their disabilities.”

EURORDIS remains dedicated to working with the newly confirmed European Commission to strengthen the European Health Union and ensure that the rare disease community has the healthcare access, treatments, support, and opportunities they need to fully engage in daily life.

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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