



## Press release

# It is time for a 'European Action Plan on Rare Diseases', concludes the Spanish Presidency Conference

**11 October, Bilbao** –Today, the Conference on Rare Diseases and the European Reference Networks, titled, '*How to guarantee European solidarity for patients?*', brought attention to critical issues regarding the integration of European Reference Networks (ERNs) into national healthcare systems and the pressing need for a European Action Plan for Rare Diseases.

Organised by the European Economic and Social Committee under the auspices of the Spanish Presidency of the EU Council, the Conference convened key stakeholders, experts, and policymakers.

In the opening session, **Stella Kyriakides**, European Commissioner for Health and Food Safety, set the tone by emphasising the necessity of a robust European Health Union. She asserted: "*A strong European Health Union is a Union that protects and cares for its citizens.*"

Kyriakides underscored the need for a revamped reform of pharmaceutical legislation to facilitate the development of more affordable medicines, particularly for rare diseases, and affirmed a commitment to tangible, targeted actions.

**Oliver Röpke**, President of the European Economic and Social Committee, echoed the sentiment that "*health and appropriate treatments are a fundamental right.*" Röpke called for European solutions, emphasising the marginalised status of those living with a rare disease.

**José Miñones Conde**, Spanish Minister for Health, underscored the need for political will, stating, "It is within our grasp, the possibility of improving the lives of people with rare diseases and their families. I think we all agree there has to be a will, a political will, behind this."

### Critical Need for EU Action Plan

Speaking on behalf of the European rare disease patient community, **Yann Le Cam**, Chief Executive Officer of EURORDIS, urged EU institutions to listen to Member States and citizens, expressing disappointment over the absence of a European Action Plan for Rare Diseases.

Le Cam declared, "*We have been developing, for over more than 20 years, the proof of concept and the instruments; we cannot wait. It is time for a public health strategy, with clear goals – to reduce mortality, social and economic impact on families, and improve healthcare outcomes. This cannot be achieved with a fragmented approach.*"

**Milan Macek** from the Czech Republic reinforced Yann's message, emphasising the need for an EU action plan for rare diseases – a key element of last year's Czech EU Presidency call to action, endorsed by 21 Member States.

**Anne-Sophie Lapointe** from the French Ministry of Health and Prevention emphasised the importance of patient-centred national policies that align with European structures, and stressed the need for a holistic approach to address high unmet needs.

Summarising, **Enrique Terol García**, Health Counsellor at the Permanent Representation of Spain to the EU, highlighted aspects that should not be compromised: *"The Commission has been doing a great job on rare diseases, and also on encouraging Member States to develop plans and share data and best practices. What we are missing now [are] a common policy with common goals to develop effective national plans."*

### **Building Infrastructure for Well-Functioning ERNs**

Speaking on the topic of European Reference Networks, **Holm Graessner**, Coordinator of ERN-RND, underscored their pivotal role serving as the main infrastructure for highly specialised care. Despite their obvious added value, Graessner acknowledged ongoing challenges, emphasising the need to enhance training and education for healthcare professionals, streamline patient journeys, optimise ERN registries, and develop guidelines and clinical decision support tools.

**Juan Carrión Tudela**, President of the Spanish Federation of Rare Diseases (FEDER), echoed the importance of ERNs from a patient perspective. He asserted, *"We have to guarantee the necessary resources for the European Reference Networks. We have to guarantee that sustainability."*

**Alexis Arzimanoglou**, Coordinator at the European Reference Network on Rare and Complex Epilepsies (ERN EpiCARE), emphasised that *"while ERNs do not conduct research directly, they play a crucial role in fostering research and innovation"*. He called for a framework of collaboration between ERNs and industry to harness the research potential of ERNs. He also stressed the importance of concerted actions to motivate the next generation of clinicians to engage in rare diseases and highlighted the complexity of diseases dealt with by ERNs.

**In concluding remarks, the Conference reinforced the collective commitment to a European Action Plan for Rare Diseases, building on existing initiatives, and underscored the urgent need for harmonised policies, increased resources, and collaborative efforts to guarantee solidarity for the 30 million Europeans living with a rare disease.**

## 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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