



Media Statement

EU conference prepares for comprehensive European action on rare diseases

29 November 2024, Budapest – Today, the European Economic and Social Committee (EESC) conference, [‘For an EU Commitment to Tackling Rare Diseases’](#), brought renewed focus to progress towards a European Action Plan for Rare Diseases by 2030.

Hosted under the Hungarian Presidency of the Council of the EU, the event underscored the importance of harmonised European policies, strengthened healthcare systems, and collective action to address rare conditions.

The conference followed the EESC’s adoption of its exploratory opinion, [‘Leaving No One Behind: European Commitment to Tackling Rare Diseases’](#), at its October plenary session. This opinion, requested by the Hungarian Presidency, calls for an integrated European health framework with specific targets for improving rare disease care by 2030. [EURORDIS warmly welcomed this opinion](#), praising its focus on solidarity, reducing diagnostic delays, and improving cross-border access to care. The recommendations – including the creation of a European Action Plan with measurable objectives and a dedicated Steering Group – align with EURORDIS’ advocacy priorities for equitable rare disease care across Europe.

During the opening session, **Baiba Miltoviča**, President of the Section for Transport, Energy, Infrastructure and the Information Society at the EESC, stated:

“We strongly believe we need an EU Action Plan on rare diseases. EU and health ministers of Member States must make rare diseases a priority ... We already have tools such as the Cross-Border Healthcare Directive and the Pharmaceutical Package; now, we need to implement these regulations and ensure proper enforcement.”

Antonio Parenti, Director at DG SANTE, European Commission, highlighted the importance of EU collaboration, recalling that ERNs are a “flagship activity with clear EU added value and a perfect example of what can be achieved when countries come together, sharing knowledge and resources to advance diagnosis, treatment, and research for rare diseases.”

Tomislav Sokol, Member of the European Parliament (EPP, Croatia), called for “a concerted strategy including research, cross-border healthcare funding, and social protection, complementing existing legislation and initiatives,” adding:

“By sharing goals and pooling resources, we can push forward research, harness digital innovation, and create healthcare systems that leave no one behind. This is about providing dignity, support, and quality of life for millions who too often go unheard.”

A key moment of the conference was the presentation of the EESC's exploratory opinion by **Ágnes Cser**, its rapporteur, who called for a European coordination body to centralise efforts, stating:

"All people suffering from rare diseases should receive a diagnosis before one year. The civil society representatives should, together with the support of EU institutions, create a coordination body to know people and families' needs, to have information in their native language. Parents should not have to travel 1,000 kilometres to know the problems of their children."

Speaking on behalf of Europe's rare disease community, **Virginie Bros-Facer**, Chief Executive Officer of EURORDIS, called for urgent and extensive action:

"No single country – not even France, Italy, or Germany – can fully address the complex challenges rare disease patients face. By pooling expertise, resources, and efforts, the EU can help bridge gaps, foster collaboration across borders, and address the unmet needs of a very vulnerable population.

"An Action Plan is not about reinventing the wheel. We have a wealth of existing resources, including the ERNs, the Joint Action JARDIN, and national rare disease strategies, that can serve as a strong foundation. However, what is urgently needed is the 'glue' to bring these elements and stakeholders together in a cohesive, organised, and coordinated manner.

"Now the time has come to turn this ask into action, and we support the call of the EESC in their recent opinion for the adoption of a Commission Communication and to start 'planning for a plan.' EURORDIS is committed to working collaboratively with all stakeholders to make this EU Action Plan a reality."

Representatives from national rare disease organisations highlighted the value of a unified European framework and the role of civil society in driving progress. **Daniel Theisen** (ALAN, Luxembourg) emphasised the transformative impact of national plans, noting, "This will work best within a European approach," while advocating for patient-centred solutions to address the diagnostic odyssey and limited treatment options. **Gábor Pogány** (RIROSZ, Hungary) stressed the need for better coordination across health, social, and education services.

Other contributors from national alliances called for greater collaboration and renewed momentum, which should translate into a European Action Plan. **Jean-Philippe Plançon** (Alliance Maladies Rares, France) urged for multidisciplinary approaches and political engagement with patients. **Lene Jensen** (Rare Diseases Denmark) described EU collaboration as a "trampoline for national initiatives, while **Annalisa Scopinaro** (UNIAMO, Italy) recalled the importance of an EU approach to newborn screening to reducing inequalities across EU countries. **Stefan Živković** (National Organisation of Rare Diseases of Serbia) highlighted the potential of the European Health Data Space (EHDS), calling it a "unique opportunity that can revolutionise healthcare for patients."

At the closing session, **Mónica García Gómez**, Minister for Health of Spain, stressed the need for coordinated action:

"Today we have a chance to change millions of lives. To do this, we need action plans in each country, a European Plan, and a global strategy. It is essential that the European Union consolidates nearly two decades of work by establishing an Action Plan for Rare Diseases."

Urszula Demkow, Undersecretary of State at the Ministry of Health, welcomed collaboration under Poland's upcoming Presidency, stating:

“We will be next for the Presidency of the Council, and we will be very happy to have you in Warsaw as the conference on rare diseases is supposed to be scheduled in April 2025. Please come to help us organise it!”

The Budapest conference reaffirmed the shared commitment of European institutions, civil society, and patient advocates to achieving a European Action Plan for Rare Diseases. Marking a shift from dialogue to action, it emphasised the urgency of drafting the plan and building the framework needed to turn this vision into reality.

EURORDIS looks forward to advancing these efforts at the rare diseases conference proposed by Poland, potentially scheduled for April 2025.

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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