



Media Statement

EURORDIS: EESC right to reaffirm call for European Action Plan for Rare Diseases

23 October 2024, Brussels – EURORDIS-Rare Diseases Europe today warmly welcomes the European Economic and Social Committee's (EESC) adoption of two Opinions relevant to the rare disease policymaking and affirming the need for greater solidarity with the rare disease community both in the EU and within the Member States.

Namely, the Opinions adopted by the EESC include:

- An Own-Initiative Opinion titled "[*Devising a European flagship initiative for health*](#)".
- An Exploratory Opinion at the request of the Hungarian Presidency titled "[*Leaving no one behind: European Commitment to Tackling Rare Diseases*](#)".

Collectively, the two opinions emphasise the need for a more integrated and inclusive health framework within the European Union, with a particular focus on solidarity and addressing health inequalities and the challenges faced by the rare disease community.

Speaking at the debate on the EESC's Opinion on a European flagship initiative for health, **Simona Bellagambi**, Vice-President of EURORDIS, said:

"We still need to work intensively to ensure that EU citizens living with a rare disease receive the solutions they need, and that we all collaborate to achieve this goal in line with the principle of solidarity.

"While competitiveness is currently a major focus, we must not forget this core value. Mr. Coheur's opinion rightly addressed this point. EU national healthcare systems need support to continue serving patients and their families effectively. Without stronger backing from the EU level, this task will be an insurmountable task.

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"Thank you [EESC] for your support – that is what we need. But this support should be translated into concrete actions, with the adoption of an EU action plan and everything we have said today. Having health as a priority in our European agenda should be a must, as well as rare diseases. It should also be developed in partnership with people living with a rare disease, and we will be most effective in addressing the unmet needs present in our lives."

Elaborating during the debate on the value of a flagship initiative for health, **Oliver Röpke**, President of the EESC, said:

"COVID may be behind us, but new challenges are in front of us, and the EESC has always been at the forefront to put health high on the EU agenda.

"Rare diseases affect 30 million of people. These people and their families are a vulnerable group and that's why we need comprehensive EU action on rare diseases."

Responding to the EESC's adopted opinion vote, **Valentina Bottarelli**, Public Affairs Director at EURORDIS, said:

"Today's adopted Opinions reaffirm the EESC's strong stance that the EU must advance towards a more equitable and inclusive health system. We are particularly encouraged by the EESC's clear call for a European Action Plan on Rare Diseases with specific, measurable targets by 2030, and the creation of a Steering Group to ensure the plan's success. These steps are vital for reducing diagnostic delays and ensuring timely access to care.

"However, we are concerned that not all EU institutions have the same level of commitment as this Committee in advocating for action on health at EU level. Yet, the COVID pandemic demonstrated how crucial cooperation between countries is, especially in the field of health and especially in the field of rare diseases.

"We fully support the EESC's emphasis on integrating the European Reference Networks into national health systems, ensuring expertise is accessible across borders. The proposed targeted investments in healthcare professions and the focus on sustainable financing are essential to improving patient outcomes."

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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