European Economic
and Social Committee

Recent
EESC achievements

Calling for an EU action plan on rare diseases

Rare diseases impact 8% of the EU population, or 36 million Europeans. With 7 000 rare diseases, most of which are chronic, disabling or life-threatening, the health and quality of life for those affected are severely compromised. Worse yet, up to 95% of these diseases lack specific treatments, and the available therapies come at exorbitant costs.

This series of fact sheets aims to show our impact on EU legislation, where we brought essential civil society issues to the EU or where we established ourselves as key players.

FOR MORE
INFORMATION

The European Economic and Social Committee (EESC) has been unwavering in its demand for a comprehensive European strategy to address the needs of people living with rare diseases.

Through a series of recommendations and conferences, we have pushed to ensure that an **EU action plan on rare diseases** is included in the next Commission's work programme. In October 2023, EU institutions, civil society organisations and patient associations came together for the first time at the EESC's conference on rare diseases in Bilbao.

In an opinion on European solidarity for patients with rare diseases, we urge the European Commission to adopt a comprehensive rare diseases policy, prioritising faster diagnosis and treatment. We also advocate leveraging the European Health Data Space (EHDS) to improve data sharing for research and diagnosis and ensuring equal access to care for all rare disease patients across the EU. We call for European reference networks (ERNs) to be fully integrated into national and EU healthcare systems. In March 2024, at the request of the European Commission and a consortium of Member States, we co-organised a conference to launch the JARDIN Joint Action, aimed at integrating ERNs into national health systems across the EU, Norway and Ukraine.

Civil society, patient organisations and experts strongly support our recommendations. EESC member **Alain Coheur**, rapporteur for the opinion, was awarded the **2024 Black Pearl Policy Maker prize** by EURORDIS, the largest EU-level civil society network for rare disease patients. In collaborating with this network, we signed an open letter to the European Commission demanding an EU action plan on rare diseases, stronger EU policies on diagnostics, treatment access, cross-border healthcare, mental health support, research funding and national strategies. Finally, on 21 June 2024, the Council adopted conclusions giving a clear mandate to the European Commission to draw up an action plan on rare diseases.

Looking ahead

We continue leading Europe's efforts to tackle rare diseases through a follow-up opinion and by holding a conference in collaboration with the Hungarian Presidency on 29 November 2024.

Patients with rare diseases should not feel alone in their fight. We are working tirelessly to build stronger EU policies that bring hope, dignity and a better future for millions of people and their families.

> **As representative of organised civil society, the EESC will continue to give patient organisations a voice and facilitate dialogue between them and European Institutions. We would like to see the new European Commission adopt a comprehensive EU Action Plan on Rare Diseases and a Special EU Financial Fund to secure access to treatment for all Europeans with rare diseases.**
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> **Cinzia Del Rio**, President of the EESC's Section for Employment, Social Affairs and Citizenship (SOC)

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