

Press release

Europe's Action Plan for Rare Diseases debated in the European Parliament

24 November 2021, Strasbourg – 19 Members of the European Parliament have debated the EU's approach to rare diseases, calling on the European Commission to adopt Europe's Action Plan for Rare Diseases by 2023.

Today, Members of the European Parliament debated rare diseases in the plenary session, calling upon the European Commission to introduce a new comprehensive, cross-cutting, and person-centred [policy framework for rare diseases in Europe](#).

The session was an opportunity for MEPs to show a united approach before the European Institutions, in calling for Europe's Action Plan for Rare Diseases, supporting the objective to build a strong European Health Union.

The debate saw a particular focus on the Commission's preparedness and, more importantly, willingness to implement the recommendations of the [Rare 2030 foresight study](#) it funded, as well as its intention to conduct a review following the [recommendations of the European Court of Auditors](#) to assess the EU's rare disease strategy and decide whether it needed to be 'updated, adapted or replaced by 2023'.

In her speech, Ms Frédérique Ries referred to the foresight study Rare 2030, stating that "the assessment of Rare 2030 was clear: we need a European Action Plan to unify our policies and bring them coherence in the medium and long term". Addressing the Commissioner Stella Kyriakides, she added: "the Parliament is with you; the Member States are with you. Postponing the issue to 2023 is in fact kicking it into touch for the next Commission".

Ms Tilly Metz on behalf of the Greens further added: "I think that the European Health Union is ready for an Action Plan on Rare Diseases, [...] which would [...] address areas such as research, diagnosis, treatments, social care, education, inclusion as well as data collection with the respect of the GDPR."

Representing the S&D Group, Ms Jytte Guteland stated: "I hope that the European Commission will take on board the conclusions of the European Court of Auditors report and follow up on what Parliament is asking them to do: to have a specific European Action Plan for Rare Diseases and clear goals. We owe it to the 30 million people living with a rare disease."

Several MEPs, including Kateřina Konečná and Tanja Fajon, also welcomed the support of the upcoming Trio presidency for making the Action Plan for Rare Diseases their priority and taking first concrete steps to align Member States.

Addressing existing inequalities in accessing health care in different EU Member States, Ms Ewa Kopacz from the EPP group emphasised the importance for "all patients from the East and the West [to] have access to [available and affordable] treatment. They deserve it".

The debate ended with closing remarks from Ms Stella Kyriakides, Commissioner for Health and Food Safety, highlighting the importance of the issue, the need for us to work together and the action to be taken, while promising to "make concrete and tangible improvements in the area of rare diseases and stand before [MEPs] again in not-so-distant future and share with you how we have moved with this".

Europe's Action Plan for Rare Diseases goes beyond improving patient access to diagnosis, information, and care. It represents a new European collective strategy for rare diseases, which sets out overarching objectives, priorities, and milestones, and connects areas, such as rare disease research and innovation, effectiveness and efficiency of national health systems, cross-border cooperation, social inclusion, and human rights of people with rare diseases at large.

Such a framework should bring Member States' commitment to rare diseases under a common umbrella, mark a step forward in the post-COVID world, and set the direction of EU health policy for the decade to come.

To further advocate for Europe's Action Plan for Rare Diseases at the European level, EURORDIS invites all stakeholders to engage directly with the President of the European Commission Ursula von der Leyen by [sharing your reason](#) for change.

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 974 rare disease patient 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 patients, families and patient 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 patient services. Follow @eurordis or see the EURORDIS Facebook page. For more information, visit eurordis.org.

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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