

21 Member States endorse Czech EU Presidency's Call to Action on rare diseases at EPSCO Council Meeting.

9 December, Brussels – The Czech Presidency of the European Union Council has today presented their Call to Action in the area of rare diseases at the [EPSCO Council](#). The call received endorsement from 22 Member States, including the Czech Republic, representing 81,6% of the EU population. This is a strong indication of the support from across the European Union towards a new comprehensive rare disease strategy.

In the presence of Health Ministers from across the European Union, Minister for Health Vlastimir Valek presented the Call to Action as a conclusive output from the Presidency Expert Conference on rare diseases in October. He said:

"[We need] a common, shared plan for our initiatives, responding to unmet needs of patients, making care accessible and comparable across the EU.

The call to action points out possibilities to create a European plan for rare diseases. The call to action was distributed among all the Member States, and [over] 20 states have expressed their support, which is an overwhelming majority.

The EU, in the area of rare diseases, is a key actor. We have a key role in creating an environment that stimulates cooperation and coordination between Member States."

The Call to Action has the overarching ambition to "adopt a European Action Plan on Rare Diseases to support and complement ongoing and future efforts at both the EU and Member State levels to reduce the unmet needs of the 20 million people living with a rare disease in the EU". It includes [several other calls](#) on improving early diagnosis, making the most of the revision of the EU's legislation on orphan and paediatric medicines, improving access to treatments, and on integrating the European Reference Networks into national health systems for more holistic care.

"22 Member States united in their call for a European Action Plan on Rare Diseases is a very strong message. This reinforces the same call from the European Parliament and agreement across all stakeholders of the rare disease community. We now have political consensus on what we know to be true: more needs to be done to improve the lives of the 20 million persons living with a rare disease in the EU.

We hope that this will serve as a wake-up call for the European Commission to unblock the road ahead to drive forward a coordinated, goals-based strategy on rare diseases in the EU."

– Yann Le Cam, EURORDIS Chief Executive Officer.

From the offset of their Presidency of the EU Council, Czechia has shown extremely strong leadership in presenting the Call to Action, in particular by hosting a two-day conference in Prague on "[Building the future together for rare diseases](#)" and a [technical meeting in July on Newborn Screening in Brno](#).

EURORDIS strongly welcomes this progress and continued support from Member States for an introduction of Europe's action plan on rare diseases – from the Ministerial Conference organised by the French Presidency in February 2022 to the EPSCO Council in March, to the high-level events by the Czech Presidency, to the EPSCO Council in December.

A European action plan on rare diseases is a health, societal and political urgency. Only with a coordinated EU strategic framework on rare diseases to bring together existing and planned efforts, with measurable short- and long-term goals, can we build an ecosystem to address the unmet needs of millions of European citizens and drive innovation forward.

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 984 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.

About 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. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings 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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