

EURORDIS-Rare Diseases Europe welcomes France's commitment to Europe's Action Plan for Rare Diseases during their Presidency of the Council of the European Union

Rare diseases feature in the Programme of the EU Council Presidency, with a High-level Political Conference announced for February

04 January 2022, Paris – EURORDIS-Rare Diseases Europe welcomes the inclusion of rare diseases on the agenda of the 2022 French Presidency of the European Union Council, as an urgent and necessary step to improve the lives of people living with a rare disease in Europe, following the announcement of the "[Ministerial Conference on Care and Research Pathways: Towards a European Policy for Rare Diseases](#)" on 28 February.

Organised by France's Ministry of Health and Solidarity on the occasion of [Rare Disease Day](#), this high-level conference, as agreed by the Trio Presidency (France, the Czech Republic, and Sweden), will bring together political figures from across Europe to set out recommendations for change to European legislation on rare diseases. It will serve as an opportunity to lay out the European Union's roadmap in this area and to collectively prepare for the adoption of a European plan for rare diseases - a comprehensive framework connecting the dots between different national and EU initiatives and policy areas.

Yann Le Cam, Chief Executive Officer at EURORDIS-Rare Diseases Europe commented:

"France has a proven track record of taking action within Europe to address the needs of persons living with a rare disease, from moving forward the Orphan Medicinal Products Regulation in 2000 to the Council Recommendation on an action in the field of rare diseases that came into force twelve years ago in 2009.

Today, France has taken an urgent and necessary step to create an ecosystem for rare diseases that will have benefits for all European citizens. No country in Europe can work slowly in the silos that currently exist without an overarching person-centred and needs-led legislative framework to link the different legislative areas and Member States' actions."

A historic leader in Europe on the issue of rare diseases, France holds the EU Council Presidency from 1 January 2022 - 30 June 2022. During its term, it is expected that it will build upon its previous leadership across EU rare disease policy, leading the call for Europe's Action Plan for Rare Diseases, including measures to improve diagnosis and person-centred care for people living with rare diseases, access to treatments and better use of data to foster research and innovation.

On 24 November, during a plenary debate, Members of the European Parliament, including French MEP Véronique Trillet-Lenoir, also [pledged their support](#) for a [European Action Plan for Rare Diseases](#), as recommended by the recent [Rare 2030 Foresight Study](#).

EURORDIS-Rare Diseases Europe, alongside the over 2100 people who have shared their [reasons for change](#), is now calling on the European Commission to respond to this call from France and the European Parliament for an ambitious European Action Plan for Rare Diseases, to deliver for the 30 million people living with a rare disease in Europe and leave no one behind.

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](#).

Rare 2030 Foresight Study

[Rare 2030](#) was a foresight study that gathered the input of over 250 patients, practitioners and key opinion leaders and thousands of people living with a rare disease to propose policy recommendations to lead us to improved policy and a better future for people living with a rare disease in Europe. This was a two-year project co-funded by the European Union Pilot Projects and Preparatory Actions Programme (2014- 2020). The study was led by EURORDIS-Rare Diseases Europe with seven academic partners and a [high-level advisory board](#) who have contributed to the development of the eight [Rare 2030 recommendations](#).

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.

Press contact

Stanislav Ostapenko
Communications Manager
EURORDIS-Rare Diseases Europe
stanislav.ostapenko@eurordis.org
+33 1 56 53 52 61