



Press release

EURORDIS Launches Pre-Election Campaign for Rare Disease Equity

Thursday, 29 February 2024, Brussels – On the occasion of Rare Disease Day, EURORDIS-Rare Diseases Europe has launched its [Championing the Rare \(#ActRare2024\)](#) campaign, which is calling on the EU's next leaders to take specific policy actions to make sure that the 30 million people living with a rare disease in Europe can have longer, healthier and better lives.

In the face of the persistent inequities and systemic failures facing people with rare diseases across the EU, the policy recommendations of the EURORDIS Championing the Rare campaign emerge as a clarion call for urgent, transformative action.

Targeting prospective European Parliament members in the June 2024 elections, nominees for the next European Commission, and other prospective EU policymakers, the [#ActRare2024](#) campaign outlines [eight vital policy domains](#) where advancements are imperative for the rare disease community and the building of a truly inclusive European Health Union.

These proposals are grounded in the findings of the landmark [Rare 2030 foresight study](#). Commissioned by the European Parliament, financed by the European Commission, and spearheaded by EURORDIS, the two-year *Rare 2030* study concluded in 2021, setting forth precise policy recommendations designed to meet specific objectives by the year 2030.

The eight key policy calls of EURORDIS' *Championing the Rare* campaign include:

1. Establishing a comprehensive European policy framework on rare diseases.
2. Promoting earlier, faster, and more accurate diagnoses.
3. Integrating national and European healthcare pathways.
4. Ensuring timely access to affordable and innovative treatments.
5. Delivering integrated, person-centred and lifelong holistic care.
6. Boosting innovative and needs-led research and development.
7. Optimising data for patient and societal benefit.
8. Supporting sustainable and resilient treatment development.

Concurrent with the launch of the Championing the Rare campaign, EURORDIS and more than 20 national rare disease alliances from across the EU have [penned a letter](#) to Ursula von der Leyen, President of the European Commission, urging the adoption of the proposed European Action Plan for Rare Diseases in the Commission's work programme for 2024-2029.

Launching the *Championing the Rare* campaign, **Yann Le Cam**, Chief Executive Officer of EURORDIS, said:

“The current situation, where people wait over five years for a correct diagnosis and where a staggering 94% of rare diseases lack a specific treatment, is not just a huge unmet medical need and morally unacceptable – it’s a stark reflection of a system that has long neglected the needs of the rare, resulting in suffering and premature death.

“Our proposals are not mere suggestions; they are a demand for equity. They are a roadmap for dismantling the barriers that have, for too long, denied people living with a rare disease the right to timely diagnosis, effective treatments, and the hope of a cure. The UN General Assembly recognised the unmet needs of this vulnerable population in its 2019 and 2023 Political Declarations on Universal Health Coverage, and, in its 2021 and 2023 Resolutions it provided to UN Member States the framework for action to address the challenges and inequities that the 300 million people with a rare disease worldwide are facing. In Europe, 23 EU Member States have already adopted or are developing their second, third or fourth generation national strategies to address the needs of people living with rare diseases and their families in an inclusive way.

“In this context, the tens of millions of families living with rare diseases in the EU have very high expectations that the new European Commission and Parliament will announce the adoption of a European Action Plan for Rare Diseases during their term. The significant unmet needs, and the exceptionally high value added to the community of EU-level action, demand a comprehensive strategy for rare diseases in Europe. This strategy should guide national policies and be integrated into European actions aimed at common goals.

“The European Union must continue to lead the way in addressing the needs of the rare disease community, promote a European model of care which inspires other regions in the world, and contribute to a more just and equitable healthcare system. It's time for the EU and its Member States to be held accountable, to ensure that in the next decade, we live in a world where no one is left behind. Let this be the moment we decide to confront the unacceptable, to turn the tide for the rare disease community.

“The time for action is now.”

The campaign launches one year after **Frédérique Ries MEP**, Chair of the [Network of Parliamentary Advocates for Rare Diseases](#), was the lead signatory of a [letter sent from 48 MEPs](#) to the European Commission President calling for a European Action Plan for Rare Diseases.

Endorsing the EURORDIS’ latest campaign, Ms Ries MEP said:

“The rare disease community rightly expects firm commitment from EU policymakers. EURORDIS’s policy proposals are more than mere suggestions; they chart a definitive course towards ensuring justice for all EU citizens with rare diseases. Fifteen years have passed since the EU’s last significant strategy on rare diseases, leading to uneven progress and the neglect of many due to the absence of a coordinated approach.

“With an increasing consensus on the need for an updated rare disease strategy, MEPs like me and candidates for the next European Parliament must pay attention to these recommendations. The European Commission faces a pivotal moment. Given that the next five-year term of the Commission will conclude in 2029, Commission must act decisively or risk failing to achieve the objectives set for measurably improving the lives of those with rare diseases by 2030.”

Reiterating the particular message about the need for a *European Action Plan for Rare Diseases*, the letter from EURORDIS and national rare disease alliances – whose publication coincides with the *Championing the Rare* campaign launch – emphasises that the Action Plan should “bridge national and European legislation, policies and programmes across the Pharmaceutical Package, the European Health Data Space, European Reference Networks, Europe’s Beating Cancer Plan, EU4Health, Horizon Europe, the European Pillar on Social Rights, the European Disability Strategy, and beyond”.

For additional details on the calls of the Championing the Rare campaign and information on how you can lend your support to the rare disease community, visit the [#ActRare2024 campaign page](#).

You can also [read the letter](#) sent from EURORDIS and national rare disease alliances to President of the European Commission Ursula von der Leyen on the need for a European Action Plan for Rare Diseases.

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.

Contact

Julien Poulain

Communications Manager

EURORDIS-Rare Diseases Europe

Julien.poulain@eurordis.org

+33 6 42 98 14 32