



Statement

## EU Disability Strategy to improve the lives of people living with a rare disease

24 March 2021, Paris – EURORDIS-Rare Diseases Europe welcomes the adoption by the European Commission of the [Strategy for the Rights of Persons with Disabilities 2021-2030](#), as part of the European Union's commitment to promoting, protecting and ensuring the full enjoyment of human rights by individuals with disabilities and complex needs.

This Strategy is of particular importance to people living with a rare disease and is extremely timely as the coronavirus pandemic continues to exacerbate vulnerabilities.

Many people with rare diseases live with motor, sensorineural or intellectual impairments and face serious challenges in their activities of daily living, including personal care and other essential tasks. Obtaining an adequate disability assessment remains one of the main obstacles for 53% of people living with a rare disease, who face inadequate assessments (34%) or do not receive an assessment at all despite needing one (19%). This affects timely access to essential tailored support and services, aggravating the high level of psychological, social and economic vulnerability experienced by people living with a rare disease.

EURORDIS particularly welcomes the following priorities of the Strategy, which echo the decade-long plea of the rare disease community and reflect the key recommendations outlined in the EURORDIS' position paper '[Achieving Holistic Person-Centred Care to Leave No One Behind](#)' (2019) as well as the [Rare 2030 multi-stakeholder recommendations on the future of rare disease policy](#) (2021):

- More awareness and support strategies for patients with disabilities related to rare diseases;
- Reforms of social protection focusing on persons with disabilities and disability assessment frameworks;
- Improved labour market outcomes of persons with disabilities, including reasonable accommodation.

"The Strategy marks yet another milestone for 30 million people living with a rare disease in Europe, many of whom live with a disability, which can often be invisible, degenerative, or varies from one day to the next. The lack of recognition of their disability is a major barrier to their participation in society on an equal basis with others. We count on the European Commission to work with Member States to introduce a strong European framework that effectively protects and supports the rights of persons with rare diseases and disability. EURORDIS is ready to contribute to the implementation of the Strategy with concrete ideas and policy

recommendations developed with its member community throughout the last few years," - says Raquel Castro, EURORDIS Social Policy Director.

**EURORDIS calls upon the Member States of the European Union to incorporate this Strategy into their national legislation to promote and protect the human rights of persons with disabilities and fulfil their obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).**

More information:

- [Feedback from EURORDIS-Rare Diseases Europe on the Disability Rights Strategy for 2021-30](#)
- [Strategy for the Rights of Persons with Disabilities 2021-2030](#)
- [Strategy for the rights of persons with disabilities 2021-2030 \(Factsheet\)](#)
- [The Post-2020 European disability strategy](#) (Study by the European Parliament)

## Contact

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## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 960 rare disease patient organisations from 73 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.

We have a long-standing history of advocating for people with rare diseases and disabilities. Since 2012, EURORDIS has been involved in different initiatives and projects, such as EUCERD Joint-Action, INNOVCare, and the European Disability Forum, to guarantee that there is no form of discrimination based on health or disability status.

## 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.