

Press release

EURORDIS joins European Disability Forum in calling on EU institutions to build an inclusive future for persons with disabilities

23 May, Brussels – Advocates from across Europe's community of persons with disabilities, including representatives from EURORDIS – Rare Diseases Europe, have formally called for a series of EU-level actions to guarantee and fulfil the rights of EU citizens with a disability.

The 5th European Parliament of Persons with Disabilities brought together over 700 delegates and EU policymakers, leading to the adoption of the Manifesto of European Disability Forum (EDF) ahead of the 2024 European Elections.

Among the EDF's Manifesto proposals are calls for:

- Guaranteeing the participation of persons with disabilities in the political and public life of the
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- Specific measures to realise the rights enshrined in the UN's Convention on the Rights of Persons with Disabilities (CRPD) for those **at higher risk of exclusion**, including people living with rare diseases.
- The EU to provide guidance and support to Member States to **improve disability assessment methods**, making sure that no one is left behind when accessing social protection and independent living schemes.
- Support to the development of a range of person-centred support services in communities **for independent living**.
- The introduction of measures to **support families of persons with disabilities**, notably those who act as informal carers.

Responding to the Manifesto's adoption, Raquel Castro, Social Policy and Initiatives Director at EURORDIS, said:

"As a community of people with diverse and complex disabilities, we fully support this Manifesto. The key priorities it outlines are not a wish list, they are essential to ensure all Europeans with disabilities can live independently and fully participate in society, while also ensuring support to their families.

"As the 2024 European elections approach, we call on prospective candidates to commit to policies such as the ones outlined in this Manifesto, to achieve a truly equitable Europe."

Among the speakers delivering an intervention at the 5th European Parliament of Persons with Disabilities was Dorica Dan, Vice-President of EURORDIS.





Welcoming the EDF Manifesto, Dorica Dan said:

"The lack of recognition of our disabilities in our Member States is a major barrier for people with rare diseases and others in the disability community who need holistic approaches. It hinders our access to our social rights at national level and to important EU initiatives for persons with disabilities, including the future European Disability Card.

"We call on all the EU institutions to support to the development of EU guiding standards on disability assessment and to further assist Member States in sharing and implementing good practices to improve national disability assessment processes".

About EURORDIS-Rare Diseases Europe

<u>EURORDIS-Rare Diseases Europe</u> is a unique, non-profit alliance of over 1,000 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 people, 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 services.

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