



Press release

EURORDIS calls for holistic care for the 30m people living with a rare disease in Europe by 2030

17 May 2019, Bucharest - EURORDIS-Rare Diseases Europe and its over 800 member organisations are today launching a new position calling for the provision of **holistic care for the 30 million Europeans living with a rare disease and their families by 2030.**

EURORDIS is launching its position '[Achieving Holistic Person-Centred Care to Leave No One Behind: A contribution to improve the everyday lives of people living with a rare disease and their families](#)' at the annual EURORDIS Membership Meeting in Bucharest, where over 200 representatives of people living with a rare disease are discussing next steps to implement the position across Europe.

The full paper is available via eurordis.org/carepaper

Dorica Dan, Member of the EURORDIS Board and President of the Romanian National Alliance for Rare Diseases, said "Today, the 30 million Europeans living with a rare disease and their family members (often the main carers) remain a marginalised and largely invisible population, with little information about their diseases and their rights, few treatments, and a high level of psychological, social and economic vulnerability."

Raquel Castro, EURORDIS Social Policy Director, commented, "This position has been developed with our members and is based on the everyday experiences of people living with a rare disease and their families. Our ambition is to have holistic care provided to all by 2030. With this position paper we aim to inspire a process that ensures people living with a rare disease have access to such care."

Ms Castro continued, "All stakeholders have an instrumental role to play in implementing the recommendations we set out. The time to act is now, particularly when the Sustainable Development Goals are calling for effective global action to ensure that no one is left behind, and while the European Pillar of Social Rights is paving the way for more effective rights equal opportunities and social inclusion in the EU countries."

Making holistic care a reality - new recommendations

The strategy to ensure holistic and integrated care for rare diseases is structured around three pillars that are explored in detail within the position:

Pillar 1

Quality and adequate social services and policies

Pillar 2

Integrated care: bridging health and social care

Pillar 3

Equity of rights and opportunities

EURORDIS and its members call upon the EU, all European countries and all stakeholders within the health and social sector to disseminate the new position and to take action based on its **ten recommendations.**

What is holistic care?

Holistic care covers the **360° spectrum of the health, social and everyday needs of people living with a rare disease and their families**. EURORDIS' ambition is to see people living with a rare disease and their families integrated in a society that provides holistic care, by:

- Being aware of their needs and effectively providing timely, high-quality care according to these needs;
- Breaking down barriers in access to care, treatment, education, employment, leisure, psychological support and all aspects of social inclusion; and
- Enabling them to fully enjoy their fundamental human rights, on equal footing with other citizens.

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About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 800 rare disease patient organisations from 70 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.