



Press release

EURORDIS responds to European Commission's mental health strategy

7 June, Brussels – EURORDIS – Rare Diseases Europe welcomes the European Commission's *Comprehensive Approach to Mental Health*, while also stressing the need for recognition of the mental wellbeing challenges specifically impacting the rare disease community.

An eagerly awaited European Commission strategy on mental health has been formally launched, following Commission President Ursula von der Leyen's first announcement of such a strategy at the [2022 State of the Union address](#).

Responding to the Comprehensive Approach, **Matt Bolz-Johnson, Mental Wellbeing Lead at EURORDIS – Rare Diseases Europe**, said:

"This initiative is a first and important milestone in renewing the political commitment to addressing the mental health needs of all Europeans. As a community of people whose majority live with disabilities and are children or young adults, the rare disease community welcomes the strategy's strong focus on the mental health of young people and its important recognition of the unfair impact of mental health challenges and inequalities on persons with disabilities.

"The new Comprehensive Approach however has fallen short of being inclusive of all groups in vulnerable situations, by not explicitly recognising Europeans living with existing physical health conditions, including chronic conditions and rare diseases. The lack of inclusion and visibility of the most vulnerable in society in key EU policies can further marginalise them and increase existing inequalities.

"We already know from our previous Rare Barometer survey that 37% of people affected by a rare condition experience unhappiness and depression, that is more than three times higher than that of the general population. This underlines the need for greater recognition that uncertainty from lengthy diagnostic odyssey, limited treatment options, and social isolation all significantly impact the wellbeing of people from across our community.

"As the Commission follows up on this initiative, they should acknowledge the mental health challenges faced by all people living in vulnerable situations. Doing so would appropriately align the initiative with progress being made globally in recognising the mental health vulnerabilities of individuals living with rare diseases or other physical health conditions.

"The World Health Organization recognises that those with pre-existing physical health conditions were at higher risk of developing mental disorders during the COVID-19 pandemic. Additionally, the United Nations General Assembly adopted a Resolution less than 18 months ago urging national

governments to implement effective programs for promoting mental health and psychosocial support for those living with rare diseases.

“Whilst we welcome the Commission's commitment to addressing mental health in all policy areas, to achieve this it remains critical for greater inclusion of those who need help the most. If it does not, then it will leave many in vulnerable situations behind.

“As the Commission moves forward, it is essential to turn the political commitment set out in this strategy into meaningful and impactful country level results, through backing up the strategy with strong measures, dedicated budget and infrastructure. Our community will eagerly support the Commission's efforts to find exemplary initiatives that enhance the wellbeing of individuals living with rare diseases in particular.”

Also responding to the Commission's Comprehensive Approach, **Kirsten Johnson, EURORDIS Board Member and Chair of the Board of Fragile X International**, said:

“For too long, the pursuit of a diagnosis, access to treatments, and the urgent drive for research into finding cures have overshadowed the profound psychological impacts of living with a rare condition.

“It is crucial to acknowledge that people living with a rare disease and their families face immense challenges. Last year, a survey led by the Genetic Alliance UK found that over 90% of them felt anxious or depressed due to their condition, with one in five reporting suicidal thoughts.

“We appreciate the European Commission's ambition in putting forward a strategy that addresses mental health in a comprehensive manner for the first time. Yet, for a truly effective response to the mental health challenges facing all of Europe's communities, the Commission must explicitly acknowledge the mental health needs of individuals with rare diseases and identify specific follow-up actions when implementing the flagship initiatives and other policies identified under the Comprehensive Approach. This would enable more complete support and holistic care for those affected, complementing the Commission's own efforts.”

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.

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