

The Impact of Rare Conditions on Mental Wellbeing Webinar

13 July 2023 at 15.00-16.30 CET



People affected by a rare and undiagnosed condition live with the accumulative impact on their mental wellbeing. Specifically at an individual level, people living with a rare disease (PLWRD) can have an associated mental health co-morbidity, whereas at a population level, the community live with the increased psychological impact associated with the rare disease journey across all stages of life. In addition, PLWRD and their families have increased exposure to social inequalities and discrimination, which are risk factors affecting poor mental wellbeing. The rare disease community have identified the need to look beyond the physiological symptoms of a rare condition, as an absolute priority, with a focus on access to psychological support as a fully integrated part of the coordination of care and made routinely available following diagnosis. Without support, there will continue to be a detrimental impact on those affected by rare conditions, hindering them from effective participation in society. However, to fully address these unmet needs, mental wellbeing needs to be seen beyond the healthcare system and in all policies and society. The new Commission Communication on a Comprehensive Approach to Mental Health, published in June 2023, is an opportunity to recognise and address the unmet needs and accumulative psychological impact on mental wellbeing of PLWRD and their families, across all policy areas.

EURORDIS held an EMM satellite workshop in Stockholm on the 25 May 2023, as part of European Mental Health Week, to engage member organisations representing rare conditions where mental wellbeing is reported as a co-morbidity and where their needs remain unmet. The webinar scheduled for the 13 July 2023 is an opportunity to share the discussions held with leaders from the rare disease community who were not able to attend the EMM satellite workshop. In addition, it is also an opportunity to take stock of the actions being taken by the European Commission now that the Communication on the Comprehensive Approach to Mental Health has been published, and identify how the rare disease community can use this refreshed political support to address mental health across Europe and in particular in the rare disease community.

WEBINAR AGENDA

Time	Topic	Speaker
15.00 – 15.05	Welcome & Opening Remarks	Avril Daly, Retina International & EURORDIS
15.05 – 15.25	Defining Mental Health & Europe - Response to addressing the Public Health Priority	Fatima Awil, Mental Health Europe
15.25 – 15.40	Impact of Mental Wellbeing on Rare Diseases	Kym Winter, Rare Minds
15.40 – 15.55	Psychological impact of diagnosis	Dr. Tom Kenny, Rare Diseases Research Partners
15.55 – 16.20	Panel Q&A	Matt Bolz-Johnson, EURORDIS
16.20 – 16.25	EURORDIS advocacy activity & the new Mental Wellbeing Partnership Network	Matt Bolz-Johnson, EURORDIS
16.25 – 16.30	Closing Remarks & Next Steps	Avril Daly, Retina International & EURORDIS

The outcome of the webinar is to launch a public call for expressions of interest to join the new EURORDIS Mental Wellbeing Partnership Network with patient representatives to partner with experts to identify common mental health needs and inform EURORDIS' strategic and policy action.