

## EURORDIS Mental Health & Wellbeing Partnership Network

### Open Webinar #5:

### EURORDIS Outline Position Paper on Mental Health

10 July 2024 at 16.30-17.30 CEST (Paris)

In this webinar, we will present EURORDIS' Outlined Position Paper on Mental Health & Wellbeing, sharing the compelling evidence and valuable insights gathered to date through our partnership network. This session aims to provide a comprehensive overview of these findings and foster an engaging discussion on their implications and future directions.

The webinar will showcase national action that has been taken to addressing the psychosocial needs of PLWRD and their families through sharing Alliance Nationale Maladies Rares experiences of providing psychosocial care for PLWRD and their families.

Registration link: <https://us02web.zoom.us/meeting/register/tZUuc-uspjIjGtPt8L6wPqaYG3ro18845vUQ>

## Agenda

| Time          | Topic  | Speaker   |
|---------------|--|---|
| 16.30 – 16.32 | <b>Welcome &amp; Introductions (2')</b>                              | Concha Mayo, EURORDIS   |
| 16.32 – 16.35 | <b>Opening Remarks (3')</b>  | Kirsten Johnson, Fragile X International & EURORDIS Board of Directors      |
| 16.35 – 16.43 | <b>Presentation of EURORDIS Position Paper on Mental Health (8')</b> | Matt Bolz-Johnson, EURORDIS   |
| 16.43 – 17.13 | <b>Best Practice on Psychosocial Care (30')</b>                      | Corinne Thill, Psychothérapeute at Alliance Nationale Maladies Rares (ALAN) |
| 17.13 – 17.28 | <b>Questions &amp; Answers (15')</b>                                 | All   |
| 17.28 – 17.30 | <b>Final &amp; Closing Remarks (2')</b>                              | Kirsten Johnson, Fragile X International & EURORDIS Board of Directors      |