

## Living with Uncertainty & Impact of Trauma

### EURORDIS 2<sup>nd</sup> Mental Wellbeing Webinar

6 September 2023 at 15.00 CET

Living with a rare condition equates to living with uncertainty and dealing with the impact of traumatic life-events. The rare disease pathway is unpredictable, paved with anxiety, fear, stress, anger and frustration, leading to increased social isolation for both the individual and family. The daily reality for many is the constant stresses associated with the coordination of multiple specialist and hospital appointment, that multi-system conditions require. The uncertainties the rare disease community face are inherent to the diagnostic odyssey, searching for an effective treatment and these uncertainties can cast a long shadow over the future. For many people living with a rare disease, these uncertainties are compounded by a traumatic history of inaccurate diagnosis, inappropriate treatment, which are concluded for a moment of certainty, when receiving an accurate diagnosis, that is quickly replaced with more uncertainty around prognosis and future outcomes. These uncertainties and traumatic events that are rooted in the rare disease pathway have been shown to increase the risk to mental health compared with the general population and as such underlines the increased vulnerability of the rare disease community to experiencing a deterioration in their mental health and wellbeing (Spencer-Tansley 2022).

### WEBINAR AGENDA

Time	Topic	Speaker
15.00 – 15.03	<b>Welcome &amp; Housekeeping</b>	Concha Mayo, EURORDIS
15.03 – 15.10	<b>Opening Remarks.</b>	Kirsten Johnson, Fragile X Society & EURORDIS
15.10 – 15.30	<b>Understanding the biopsychosocial continuum and addressing intersectional needs.</b>	Péter Kéri, GAMIAN Europe
15.30 – 16.00	<p><b>Panel discussion:</b> living with uncertainty and impact of trauma.</p> <ul style="list-style-type: none"> <li>- Understanding of the root cause of the uncertainties and trauma associated with the rare disease pathway.</li> <li>- Identifying coping strategies to deal with uncertainty of the rare disease journey.</li> <li>- Identifying training needs for professionals to reduce the stressors associated with a rare disease.</li> </ul>	<p>Chair: Matt Bolz-Johnson</p> <p><b>Panel:</b></p> <ul style="list-style-type: none"> <li>- Kym Winter, Rare Minds</li> <li>- Lucy McKay, Medics 4 Rare Diseases</li> <li>- Dorica Dan, Romanian Prader Willi Association</li> </ul>
16.00 – 16.10	<b>Questions &amp; Answers</b>	All
16.10 – 16.25	<b>Impact of living with a congenital malformations on mental wellbeing of the family.</b>	Rosanne Smit, Radboud University Medical Centre
16.25 – 16.30	<b>Closing Remarks &amp; Next Steps</b>	Kirsten Johnson, Fragile X Society & EURORDIS

The outcome of the webinar is to make a final 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.