

# Webinar on *'How do rare conditions impact family and social relationships?'*

**EURORDIS 8<sup>th</sup> Mental Health & Wellbeing Webinar 19.12.2024 at 11.30-13.00 CET**

Family, peer and social relationships are key for mental health and emotional wellbeing. Relationships within a family are impacted in diverse and complex ways when a family member (or members) live with a rare condition. Family relationships can be complicated at the best of times, and both the diagnosis of, and living with, a rare condition adds an additional layer of complexity. Every family member is impacted by, and makes meaning of their experiences, over time in their own unique way. Individuals often face difficult (and sometimes conflicting) emotions about the impact of the condition on those they are close to, whether from the perspective of affected person, partner, parent or sibling. This emotional impact can extend across generations too.

Social and peer interactions can also involve challenges. A rare condition may evoke less empathy or support than a more common condition. Visible differences can lead to bullying, loneliness, or isolation; invisible disabilities (whether physical, or neuro-cognitive/intellectual) may be either 'forgotten', or misunderstood. The intensity of family relationships can at times become heightened as a result of unmet needs for social or peer support.

This webinar will explore how rare conditions shape and inform social and family relationships, drawing from the lived experience of affected individuals, caregivers and parents, and siblings. The outcome of the webinar will be a factsheet to help increase awareness about the impact of rare conditions on both social and family relationships, and how to support these.

## WEBINAR AGENDA

Time	Topic	Speaker
11.30 – 11.35	<b>Welcome and opening remarks</b>	Matt Bolz-Johnson, EURORDIS
	<b>Roundtable discussions exploring:</b> <ul style="list-style-type: none"> <li>• how rare conditions shape and impact personal relationships</li> <li>• the challenges and strategies for resilience, and supporting relationships</li> </ul> Discussions moderator : Kym Winter (Rareminds)	
11.35 – 12.00	<b>Roundtable 1: Perspective of people living with a rare condition</b>	<b>Panelists:</b> <ul style="list-style-type: none"> <li>• Sheila Khawaja, Pituitary Adenoma</li> <li>• Daniel de Vincente, FEDER &amp; EURORDIS Board of Directors</li> </ul>
12.00 – 12.25	<b>Roundtable 2: Parents perspective, and the impact on the couple relationship</b>	<b>Panelists:</b> <ul style="list-style-type: none"> <li>• Susana Carvajal, Mother of a child with a rare kidney condition</li> <li>• Tomasz Grybek, Foundation of Borys the Hero &amp; EURORDIS Board of Directors</li> </ul>
12.25 – 12.50	<b>Roundtable 3: The siblings perspective</b> <ul style="list-style-type: none"> <li>• Questions &amp; Answers</li> </ul>	<b>Siblings:</b> <ul style="list-style-type: none"> <li>• Regla Maria Garci Espejo, Psychologist at FEDER &amp; Sibling of someone living with West Syndrome</li> </ul>
12.50 – 12.55	<b>Questions &amp; Answers</b>	All
12.55 – 13.00	<b>Closing Remarks</b>	Matt Bolz-Johnson, EURORDIS