

# Webinar on ‘How to deliver a diagnosis’



## EURORDIS 6<sup>th</sup> Mental Health & Wellbeing Webinar

23<sup>rd</sup> of October 2024 – From 13.30 pm to 15.00 pm CET (Paris time)

The diagnosis of a rare disease is a critical milestone for families and individuals affected by rare conditions. It marks the end of a journey of uncertainty and anxiety, but it can quickly be replaced by significant feelings of fear, stress, and guilt.

The way a diagnosis is communicated can have profound effects. When delivered with empathy and clarity, a diagnosis can empower families and individuals to face the challenges that living with a rare condition brings. However, when handled poorly, it can exacerbate emotional distress, impact on our relationships and disrupt our lives. All too frequently too many in the rare disease community experience inadequate communication during diagnosis. The impact of poor communication of a diagnosis can cast a dark shadow across the future healthcare pathway and erode trust in all medical professionals.

This webinar aims to explore real cases and best practices for delivering a rare disease diagnosis effectively, presented by experts from European Reference Networks (ERNs) such as ERN CRANIO, ERN-EYE, and VASCERN. Following these presentations, a panel of specialists from various fields will engage in a discussion to highlight identify best practice on how to deliver a diagnosis and ensure individuals and their caregivers, families can access the psychosocial support they need.

### WEBINAR AGENDA

Time	Topic	Speaker
13.30 – 13.34	<b>Welcome and opening remarks</b>	Concha Mayo, EURORDIS
13.34 – 14.10	<b>Best practice presentations on how to deliver a diagnosis:</b> <ul style="list-style-type: none"><li>• ERN EYE</li><li>• ERN Cranio</li><li>• VASCERN</li></ul>	Each presentation is 12 minutes (including Q&A) <ul style="list-style-type: none"><li>• Catherine Clermont-Vignal &amp; Caroline Wernert Iberg</li><li>• Gareth Davies &amp; Marizela Kljajic</li><li>• Anne-Mette Bredahl &amp; Elisabeth Lisack</li></ul>
14.10 – 15.40	<b>Panel discussion:</b> <ul style="list-style-type: none"><li>• Identifying the protection factors and tools that can reduce the mental health impact of living through the diagnostic odyssey.</li></ul>	Chair: Matt Bolz-Johnson, EURORDIS Panellists: <ul style="list-style-type: none"><li>- Andre Rietman, Psychologist at ERNICA</li><li>- Sara Talarico, Clinician and Resercher at ERN ReCONNET</li><li>- Gareth Davies, European Cleft Organisation</li><li>- Gulcin Gumus, EURORDIS</li></ul>
15.40 – 15.55	<b>Questions &amp; Answers</b>	All
15.55 – 15.00	<b>Final &amp; Closing Remarks</b>	All Panellists & Matt Bolz-Johnson, EURORDIS

The outcome of the webinar will be a factsheet to help increase awareness about the common mental health needs and how to address them, for the rare disease community.