

**Shaping the Future:
Policy Responses to Rare Neurological Challenges**

**19 February 2025, 10:00 – 12:00hrs CET
European Parliament, ASP 5G1**

The event is hosted by MEP Billy Kelleher (Renew Europe, Ireland)

MEETING AGENDA

OPENING REMARKS

MEP Billy Kelleher (Renew, Ireland) 10:00 – 10:05

WELCOME

Astri Arnesen, President, European Federation of Neurological Associations (EFNA) 10:05 – 10:15
A Call to Action for Rare Neurology and The Rare Neurology Charter

PRESENTATION

Dr Orla Galvin, Executive Director, European Federation of Neurological Associations (EFNA) 10:15 – 10:25
New Health Technology Assessment (HTA) legislation and disparities in access across Europe

PANEL 1 DISCUSSION: ‘Does current policy meet the needs of the rare neurology community?’ 10:25 – 10:50
Moderated by Astri Arnesen

- Insights from Arabela Acalinei, European Alliance of Neuromuscular Disorders Associations (EAMDA)
- Insights on ERN-RND from Dr. Holm Graeßner, European Reference Network (ERN)
- Insights on Dravet Syndrome from Jose Ángel Aibar

PANEL 2 DISCUSSION: ‘The impact of rare neurological conditions, through the lifecourse’ 10:50 – 11:15
Moderated by Astri Arnesen

- Insights on Dystonia from Merete Avery, Dystonia Europe
- Insights on Myasthenia Gravis from Lut Allard, European Myasthenia Gravis Association
- Insights from Jean-Philippe Plançon, European Patient Organisation for Dysimmune and Inflammatory Neuropathies (EPODIN)

REFLECTIONS FROM MEPS

MEP Tilly Metz (Greens/EFA, Luxembourg), MEP Tomislav Sokol (EPP, Croatia), 11:15 – 11:35
MEP Margarita de la Pisa Carrión (Pfe, Spain), MEP Ondřej Dostál (Independent, Czechia),
MEP Romana Jerković (S&D, Croatia), MEP Cynthia Ní Mhurchú (Renew Europe, Ireland)

CLOSING REMARKS

Astri Arnesen, President, European Federation of Neurological Associations (EFNA) 11:35 – 11:40

COFFEE & NETWORKING 11:40 – 12:00