

Rare Neurological Diseases in the EU- The Importance of Early Diagnosis and Real World Evidence to Drive Better Patient Outcomes

7 December 2022, 16:00 CET

Room ASP 5E1

European Parliament, Brussels

16:00- 16:10	<p>Introduction and welcome Tilly Metz, Member of the European Parliament (Luxembourg, Greens/EFA)</p>
16:10-16:25	<p>EU initiatives in rare diseases- European partnership on rare diseases under Horizon Europe Christina Kyriakopoulou, European Commission, Directorate-General for Research and Innovation (DG RTD)</p>
16:25-16:35	<p>Urgency of Early Diagnosis for rare diseases- the patient perspective Els Roelandt, Sumaira Foundation</p>
16:35-16:50	<p>The need for Real World Data for early diagnosis Orla Galvin, Federation of Neurological Associations (EFNA)</p>
16:50- 17:05	<p>Value of Treatment for Rare Neurological and Neurometabolic Disorders case study results and 2022 call to action Frédéric Destrebecq, European Brain Council (EBC)</p>
17:05-17:15	<p>The importance of aligning research and the importance of Real World Evidence for rare diseases Kumaran Deiva, Rare Immunodeficiency, Autoinflammatory and Autoimmune Diseases Network (ERN-RITA)</p>
17:15-17:30	<p>Discussion and wrap up Moderated by Neil Betteridge, European Alliance for Patient Access (EAFPA)</p>

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