

Towards a Rare Brain Disease Ecosystem

Day: 29th February 2024 – Rare Disease Day

Duration: 10.00 - 14.00

Location: Francqui Room, University Foundation, Rue d'Egmont 11, 1000 Brussels, Belgium

Aim

To raise awareness on rare brain disease, this event will bring together researchers, clinicians, persons living with brain disease and industry to share their perspectives and priorities in the rare brain disease research, care, and policy space. This will result in the 2024 strategic plan for the EBC rare brain disease ecosystem.

Preliminary Agenda

Session 1: Welcome and opening

10.00 - 10.05 Welcome

Frédéric Destrebecq, European Brain Council, Executive Director

10.05 - 10.10 Opening Address

TBC

10:10 – 10:25 The MOONSHOT initiative

TBC

Session 2: Patient and caregiver priorities

10.25-10.35 A testimony

Tim Buckinx, Epihunter

10:35 – 10:45 Mental health in people living with a rare disease

Matt Bolz-Johnson, EURORDIS

10.45-10.55 The rare neurology charter

Orla Galvin, European Federation of Neurological Associations (EFNA)

Session 3: Industry innovation trends	
10.55-11.05	Neuromyelitis optica spectrum disorder (NMOSD) and Myasthenia Gravis (gMG) <i>Matthias Heck, Alexion</i>
11.05-11.15	Epilepsy & Rare Syndromes <i>TBC</i>
11.15-11.25	Amyotrophic Lateral Sclerosis, a rare neurodegenerative disease <i>Lugdivine Le Dez, Amylyx</i>
Session 4: Clinical care pathways for rare disease in Europe	
11.25-11.35	The case of ataxia <i>Paola Giunti, Ataxia UK</i>
11.35-11.45	The case of phenylketonuria <i>Anita MacDonald, Dublin Misericordiae</i>
11.45-11.55	Towards a digital care pathway? <i>Giuseppe Turchetti, Scuola Superiore Sant'Anna</i>
11.55-12:05	Bringing Artificial Intelligence home for a better care of amyotrophic lateral sclerosis <i>TBC</i>
Session 5: Open Discussion: Unmet needs	
12.05-12.35	Healthcare professional perspective <i>Anna Jansen, European Paediatric Neurology Society (EPNS)</i> <i>Michelangelo Mancuso, European Academy of Neurology (EAN)</i> Regulatory perspective Belgian EU presidency perspective
12.35-12.40	Wrap up and closing remarks <i>Frédéric Destrebecq, European Brain Council, Executive Director</i>
12.40-14.00	Networking Lunch

