



# Towards a Rare Brain Disease Ecosystem

Rare Disease Day 2025 "More Than You Can Imagine"

University Foundation, Brussels

20 February 2025 | 09:30 - 14:00

## **Towards a Rare Brain Disease Ecosystem**

### **Rare Disease Day 2025 Theme “More Than You Can Imagine”**

**Day:** In the framework of Rare Disease Day, Thursday 20 February 2024

**Duration:** 09.30 - 14.00

**Location:** Room A, University Foundation, Rue d’Egmont 11, 1000 Brussels, Belgium

The main purpose of Rare Disease Day is to raise awareness about rare diseases and their impact on the lives of those affected. In the continuity of the European Brain Council’s (EBC) activities on rare brain diseases, EBC introduced in 2024 the concept of a Rare Brain Disease Ecosystem to engage key stakeholders in the field to identify gaps, priorities, and projects in Europe. During this event, the Rethinking Myasthenia Gravis (MG) project will be launched. Researchers, clinicians, persons living with brain disease and industry will share their perspectives and priorities in the rare brain disease research, care, and policy space, and will brainstorm on how care and treatment pathways for rare brain diseases such as MG, Neurofibromatosis Type 1 and Rare Epilepsy can be optimised from both the patient and clinician perspectives. It will be also the opportunity to further discuss the objectives and value add of the proposed EBC Rare Brain Disease Ecosystem & Knowledge Hub.

#### ***Proposed Agenda***

**9.30 - 10.00 Registration & Welcome Coffee**

**Session 1 Welcome and Opening**

**10.00 - 10.05 Welcome**

**10.05 - 10.15 Opening Address**

**10.15 – 10.30 Telling the Story: “Waiting for Zoro”, the story of a child with a rare brain disease and related severe disabilities**

Sarah Moon Howe, Filmmaker

**10.30 – 11.00 Policy Commitment to Tackling Rare Diseases**

**11.00 - 11.30 Coffee Break**

**Session 2    Unmet Needs and Patient Care pathways for Rare Disease in Europe**

**11.30 - 12.20** *Moderator: Vinciane Quoidbach, European Brain Council*

**The patient perspective**

**Panel discussion**

**The Patient Care Pathway methodology: the organisational and economic perspective**

**Clinical perspective**

**Industry perspective on MG**

**Towards a Rare Brain Disease Ecosystem & Knowledge Hub: Open Discussion**

**Session 3**

**12.20 - 12.50** *Moderator: Frederic Destrebecq, EBC Director*

**A multistakeholder perspective**

**Panel discussion**

Interaction with the Audience: Q&A

**12.50 - 13.00** **Wrap up and Closing Remarks**

**13.00 - 14.00** **Networking Lunch**

