EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

The Invisible Issues of Neurological Conditions

RARE NEUROLOGY DATA

RESULTS OF THE 2024 SURVEY

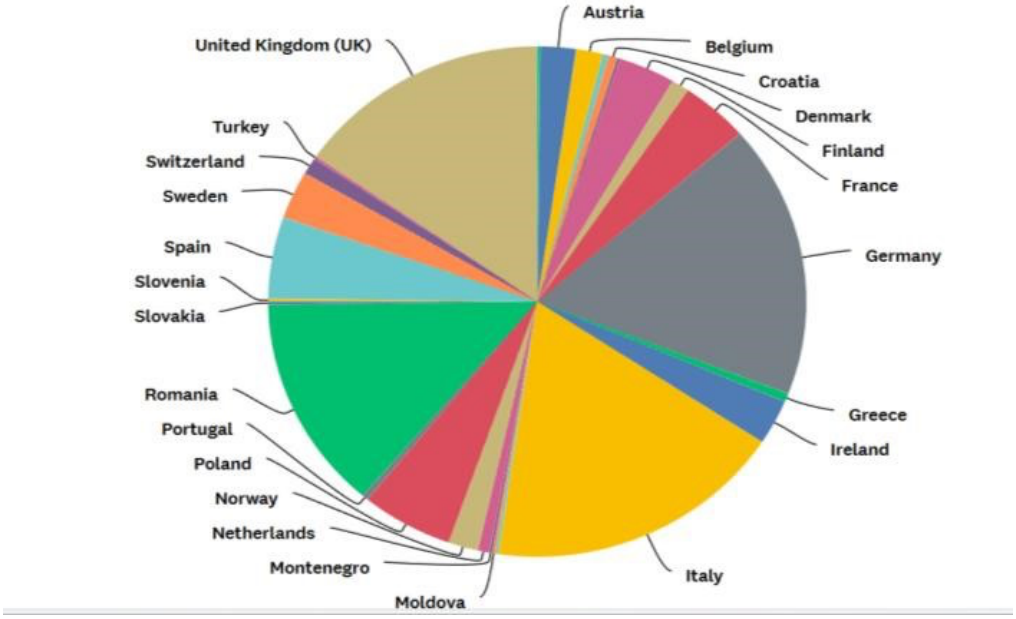
BY THE EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

Rare Neurology Data Collected 2024 (n=560)

EFNA Survey on Invisible Issues of Neurological Conditions

Most respondents were female (82%), with 17% male and 1% identifying as another gender. Most participants (92%) responded as a person living with a rare neurological condition, while 8% responded as a caregiver.

Respondents ranged in age from 18 years to 65 years and older, with the majority aged between 35 and 64 years. The highest number of responses came from Germany, Italy, Romania, and the United Kingdom, ensuring broad European representation.



The most represented rare neurological conditions among respondents were myasthenia gravis (39.46%, n=221), dystonia (34.29%, n=192), and Charcot–Marie– Tooth disease (11.96%, n=67), with additional responses covering a wide range of other rare neurological conditions.

Respondents reported a high burden of frequent multi-system symptoms, the findings highlight the pervasive and ongoing nature of symptoms affecting daily functioning and quality of life. There most frequent and prevalent invisible physical issues were reported as:

- Fatigue – 82.72%
- Pain – 66.45%
- Sleep problems – 61.33%
- Dizziness or balance issues – 50.00%
- Cognitive problems (e.g. memory or concentration) – 46.40%
- Stomach upset, constipation or urinary difficulties – 44.56%
- Mental health issues (such as depression or anxiety) – 34.08%
- Sexual health problems – 28.21%

Social and structural impacts—particularly stigma, strained relationships, isolation, and employment challenges—are experienced moderately to very severely by the majority of respondents. This underlines that rare neurological conditions affect far more than health alone, with profound consequences for social participation, economic security, and quality of life, reinforcing EFNA's advocacy focus on integrated, rights-based, and socially informed care and policy responses.

Respondents indicated the most frequent social and structural issues were:

- Stigma – 74.47%
- Relationship issues (family and friends) – 77.29%
- Isolation – 74.27%
- Employment issues – 70.17%
- Education barriers – 43.13%
- Gender-related issues – 39.48%

EMPLOYMENT ISSUES:

- **62%** indicated that their rare neurological condition makes their work life more difficult.
- **69.84%** indicated that they had to adjust their work to accommodate their condition.
- Only **40%** indicated that their employer was supportive of this.

The greatest fear was that people would think less of them and that they were not capable, followed by a fear of losing their job, followed by a fear of discrimination, and then joint last, being made fun of or a fear of not getting promotions. 32% said it affected their workplace relationships.

When it comes to social life:

- **82%** indicated that they did not attend a social or family event as a result of their rare neurological condition.
- Only **38%** indicate that they're comfortable talking about their condition with family and friends.
- For parents, **16%** have been made feel like they're not a good parent because of their rare neurological conditions.

MEDICAL INTERVENTION:

- **81.5%** indicated that healthcare professionals at times did not believe the extent or severity of their symptoms.
- **77.6%** indicate that they believe that they were not receive appropriate treatment because a medical professional did not take them seriously enough.

- **50%** indicated that they had difficulty accurately describing their symptoms to a doctor.
- **65%** were initially misdiagnosed.

FINANCES:

- **76%** indicate that their cost of living has increased significantly because of their neurological condition.
- **69%** indicate that their income has been negatively affected because of their neurological condition.
- **22.7%** were denied insurance or a mortgage on account of their rare neurological condition.
- Only **51%** have access to a disability benefit.

STIGMA:

Respondents believe the stigma experienced is due to

- the invisible nature of the condition is the greatest cause of stigma at **34%**,
- a lack of understanding of the condition at **25.5%**,
- the symptoms of the condition at **17.5%**,
- because it's neurological **8.6%**,
- misconceptions **7.4%**,
- and the name of the condition **6.8%**.

The area in which stigma has been most problematic is:

- the interaction with medical professionals at **31.44%**,
- followed by employment at **25.45%**,
- followed by interaction with the public at **16.77%**,
- then interaction with family and friends at **7.78%**,
- then in romantic relationships **7.49%**,
- and then during education at **5.09%**.

RECOMMENDATIONS

When it comes to policy there are many frameworks already in place that must be implemented to ameliorate the above-mentioned issues faced by those living with rare neurological conditions.

We ask policy makers when considering Brain Health and Neurology policy that these pre-existing opportunities are meaningfully included as they have the capacity to improve:

- Physical function
- Cognitive health
- Mental well-being
- Social participation
- Economic security

1. Rights, Disability & Quality-of-Life Frameworks such as…

- UN Convention on the Rights of Persons with Disabilities (CRPD)
- EU Strategy for the Rights of Persons with Disabilities 2021–2030
- WHO Global Disability Action Plan (linked to UHC & NCDs)

Outcome focus: *Dignity, participation, independence, social inclusion*

- Legal recognition of disability and invisible neurological conditions
- Reduced stigma and discrimination
- Improved access to education, employment, social protection
- Independent living and community participation
- Patient-centred quality-of-life measures embedded in policy

2. Rare Disease, Neurology & Cross-Border Care

- WHO Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP 2022–2031)
- EU Council Recommendation on an Action in the Field of Rare Diseases (2009)
- Directive 2011/24/EU on Patients' Rights in Cross-Border Healthcare
- European Reference Networks (ERNs)

- Commission Implementing Decision 2014/287/EU (ERN criteria & evaluation)

> ***Outcome focus:*** *earlier diagnosis, equitable access, reduced burden*
>
> - Shorter diagnostic journeys for rare neurological conditions
> - Access to specialised expertise via ERNs
> - Cross-border access to diagnosis and treatment
> - Reduced geographic and socioeconomic inequalities
> - Better care coordination for complex, multisystem conditions

3. Data, Digital Health & Registries

- European Health Data Space (EHDS) Regulation
- General Data Protection Regulation (GDPR)
- EU data governance frameworks supporting registries & secondary data use

> ***Outcome focus:*** *continuity of care, visibility, system learning*
>
> - Interoperable patient records across borders and settings
> - High-quality rare disease and neurology registries
> - Improved disease surveillance and care planning
> - Evidence generation for unmet needs and QoL impact
> - More efficient health systems through secondary data use

4. Research, Clinical Trials & Patient Involvement

- Clinical Trials Regulation (EU) No 536/2014
- EUPATI Framework & Guidance on Patient Involvement in Medicines R&D
- EMA & EU ethics guidance on patient engagement in trial design

***Outcome focus:** relevance, trust, real-world benefit*

- Clinical trials that reflect patient priorities and lived experience
- Improved recruitment and retention in rare disease trials
- Meaningful patient-reported outcomes (PROs) and QoL endpoints
- Ethical, inclusive, and accessible trial design
- Faster translation of research into real-world benefit

5. Medicines, Innovation & Market Access

- Orphan Medicinal Products Regulation (EC) No 141/2000
- Paediatric Regulation (EC) No 1901/2006
- EU Pharmaceutical Legislation Revision (2023–)
- Health Technology Assessment Regulation (EU) 2021/2282
- EU4Health Programme Regulation (EU) 2021/522
- European Biotech Act (proposed Dec 2025)

Outcome focus: availability, affordability, sustainability

- Increased development of therapies for rare neurological conditions
- Earlier and more equitable access to approved medicines
- Better alignment between regulators, HTA bodies, and patients
- Recognition of QoL benefits in value assessment
- Sustainable innovation ecosystem for rare and neurological diseases

Across all five buckets, the combined outcomes support cross-cutting quality-of-life impact.

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RARE NEUROLOGY

Sign now and show your support for the development of rare neurology action plans at EU-level which will aid policy change.

www.efna.net/RNC-CTA

SCAN HERE

For further information contact **info@efna.net** or visit **www.efna.net**

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