RETHINKING MYASTHENIA GRAVIS

POLICY BRIEF

Rethinking Myasthenia Gravis Care Through a Brain Health Lens

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Introduction

Myasthenia gravis (MG) is a rare autoimmune neuromuscular disorder that places a substantial clinical, socioeconomic, organisational, and mental health burden across Europe. Beyond muscle weakness and fatigability, MG is associated with broader brain health impacts, including persistent fatigue, cognitive strain, anxiety, depression, sleep disruption, and reduced social participation. These aspects are not consistently addressed in care models, which remain largely focused on neuromuscular symptom control.

Rethinking Myasthenia Gravis is a two-year, multistakeholder, research-driven initiative (2025–2026) designed to develop evidence-based recommendations to improve care pathways and patient outcomes for people living with myasthenia gravis (MG) across Europe. The project is part of the European Brain Council's (EBC) Rare Brain Disease Ecosystem flagship initiative and is led by EBC in collaboration with the Institute of Management at the Sant'Anna School of Advanced Studies (SSSA) in Pisa, Italy. Bringing together researchers, clinicians, patient representatives, European Reference Networks (ERNs), notably ERN EURO-NMD, and policymakers, the project aims for a coordinated and future-oriented rethinking of MG care.

"Rethinking MG" brings together scientific evidence, patient perspectives, and policy insights to inform care pathways, access mechanisms, and regulatory decision-making across Europe. European and international agendas increasingly converge on earlier and more accurate diagnosis, strengthened care pathways and centres of expertise, equitable access to effective treatments, high-quality data and registries, and coordinated action through European Reference Networks, the EU Health Technology Assessment (HTA) Regulation, and the European Health Data Space (EHDS).

MG illustrates a twofold challenge. Scientific progress has accelerated, including improved antibody detection methods (notably cell-based assays) and a widening array of targeted immunotherapies that have transformed the treatment landscape. These innovations enable steroid-sparing strategies, reducing long-term corticosteroid exposure and its cumulative risks, including metabolic, psychiatric, and cognitive side effects.

However, health system adaptation has not kept pace. Persistent diagnostic delays, fragmented care pathways, uneven access to specialist centres and innovative therapies, and inconsistent integration of outcome measures and digital tools into routine care limit the translation of innovation into day-to-day patient benefit.

This policy paper is the outcome of three focus areas: highlighting the socio-economic burden of myasthenia gravis (MG), optimising patient care pathways for MG from both patient and clinician perspectives, and developing policy recommendations to inform health policy by involving the entire MG community.

It focuses on five key priorities: embedding multidisciplinary care pathways, ensuring equitable and evidence-informed access to innovative therapies, addressing the socioeconomic and psychological burden for patients and caregivers, reducing diagnostic delay and misdiagnosis, and harnessing digital tools and data for better MG management.

Policy Recommendations

These recommendations position MG as a practical case for translating rare disease and brain health commitments into improved care, while contributing to the implementation of European and global policy frameworks.

EU level

- Strengthen European coordination of MG expertise through ERN EURO-NMD and its integration with national centers of expertise, referral networks and tele-expertise services.
- Support the development of common principles for MG care pathways across Europe, including timely referral, access to appropriate diagnostics, multidisciplinary care and systematic outcome measurement. See below national level.
- Ensure that European HTA collaboration and related national assessments consider outcomes meaningful to people living with MG, including functioning, fatigue, quality of life, treatment burden and long-term corticosteroid exposure.

National level

- Integrate MG within national rare disease and neurological disorder strategies, with clearly defined referral pathways, designated expert centers and links to European expertise.
- Increase MG awareness and training among primary care professionals, emergency physicians, nurses, non-neurology specialists and general neurologists to reduce diagnostic delay and misdiagnosis.
- Ensure timely and equitable access to core diagnostics (neurophysiology, antibody testing, including broader access to validated cell-based assays (CBAs) when appropriate), and evidence-based treatments, supported by transparent access and reimbursement pathways.
- Systematically integrate mental health screening, management of fatigue and cognitive impairment, access to appropriate rehabilitation, and psychosocial support into MG care pathways, alongside motor symptom control.

- Promote flexible work arrangements, workplace adaptations, and social protection mechanisms for people living with MG.
- Develop structured caregiver support, including respite, counseling, and information on rights and entitlements.
- Scale up MG-relevant telemedicine, remote monitoring, and wearable-based tracking in routine care.
- Co-design digital tools with patients and caregivers to ensure accessibility and usability.

Global level

- Ensure that rare neurological and neuromuscular disorders, including MG, are reflected in the implementation of the WHA Resolution on Rare Diseases and WHO IGAP, and inform the development of the forthcoming WHO global action plan on rare diseases.
- Advance universal health coverage for people living with rare neurological diseases by improving equitable access to affordable diagnostics, effective treatments, rehabilitation, psychosocial support and social care, without financial hardship.
- Strengthen regional and international centers of expertise, referral networks and tele-expertise mechanisms to reduce diagnostic and treatment gaps, particularly in underserved and resource-limited settings.
- Promote interoperable rare disease registries and information systems, using appropriate coding and nomenclature, to support surveillance, research, real-world evidence and patient-reported outcomes.
- Ensure meaningful involvement of people living with MG, families and caregivers in policy development, research priorities and monitoring of implementation, with attention to equity, human rights and social participation.
- Mobilize international research collaboration and sustainable financing to address diagnostic delay, access to treatment, long-term outcomes, prevention of avoidable deterioration and care delivery in low-resource settings.
- Develop measurable indicators to monitor progress in diagnosis, access to specialist care and treatment, patient outcomes, social participation and financial protection.

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Rethinking Myasthenia Gravis (MG) is a 2-year multistakeholder research-driven project offering policy recommendations to make tangible changes with the aim to improve the lives of people living with Myasthenia Gravis across Europe. The project officially kicked off during EBC's Rare Disease Day 2025 event, `Towards a Rare Brain Disease Ecosystem`.

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