

Call for action

Recommendations from European Leaders and All United for MG coalition for the improvement of the visibility, recognition and treatment of Myasthenia Gravis (MG)

The European policy framework established over the past two decades has undoubtedly led to major successes, be it in terms of medical innovation promoted by specific incentives, in terms of knowledge and information sharing thanks to the European Reference Networks and European Platform for Rare Disease Registration, and in terms of disease management thanks to dedicated national rare disease strategies. **EU rare disease policy is headed for a major overhaul with the ongoing revision of the OMP Regulation and discussions on a potential “EU Rare Disease Action Plan”.**

There is a growing consensus that more can be done to address the needs of rare disease patients and of their families and caregivers, whose crucial role in disease management is often forgotten. To contribute to this discussion, a group of MG patient organisations from 7 different EU countries under the banner All United for MG, have joined forces to shed light on the needs that still need to be met from the perspective of patients and their caregivers and, on that basis, to develop concrete recommendations. While these recommendations focus on MG, their relevance can be extrapolated for rare disease management more broadly.

About the disease

Myasthenia gravis (MG) is a serious, rare, and chronic neuromuscular autoimmune disease where antibodies can cause debilitating and potentially lifethreatening muscle weakness.^{1,2} Put simply, the body's natural defences are not working the way they're supposed to.³ It often starts in the face, with first signs including eye muscle weakness that can lead to drooping eyelids and double or blurred vision.^{4,5,6} MG also affects muscles involved in talking, chewing, swallowing, and breathing, and can extend to the arms and legs.^{7,8,9}

Up to 123,000 people across Europe are suffering from MG – with a significant impact on daily life.^{10,11} It can disrupt routines at home, school and/or in the workplace. And this can go on to affect family, social circles, education or career progression, as well as physical and mental wellbeing.¹²

¹Gilhus NE, et al. *Nat Rev Dis Primers*. 2019;5(1):30.

²Stetefeld H, et al. *Neurol Res Pract*. 2019;1(19):1-6.

³Gilhus NE, et al. *Nat Rev Dis Primers*. 2019;5(1):30.

⁴Idem.

⁵Stetefeld H, et al. *Neurol Res Pract*. 2019;1(19):1-6.

⁶Mantegazza R, et al. *Ann N Y Acad Sci*. 2003;998:413-23

⁷Gilhus NE, et al. *Nat Rev Dis Primers*. 2019;5(1):30.

⁸Stetefeld H, et al. *Neurol Res Pract*. 2019;1(19):1-6.

⁹Mantegazza R, et al. *Ann N Y Acad Sci*. 2003;998:413-23

¹⁰Bubuioc AM, et al. *J Med Life*. 2021;14(1):7-16.

¹¹Szczudlik P, et al. *Front Neurol*. 2020;11:553626.

¹²Idem.

We are calling the European Commission, the European Parliament, the Council of the EU, Member States, Health Authorities and all healthcare stakeholders (healthcare professionals, research community, industry and civil society) to:

Our recommendations aiming at enhancing the EU's role in rare disease management

Improving medical care

- *Expand knowledge and expertise of rare diseases and reduce diagnosis errancy by ensuring that healthcare professionals, both GPs and specialists, such as neurologists and ophthalmologists for MG, have easy access to informative resources and materials on the disease.*
- *Reinforce cross-border cooperation for the treatment of rare diseases like MG, notably by ensuring that patients are eligible for reimbursement of treatments received in another EU Member State.*

Widening social care and support

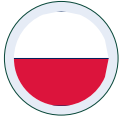
- *Raise awareness about the disease amongst the wider public by creating a European day dedicated to myasthenia gravis, in coordination with stakeholders in each EU Member States.*
- *Ensure mutual recognition of MG patients' disability status and its associated benefits across all EU Member States. This can be achieved by introducing EU-wide the "EU disability card" already in voluntary use in eight countries.*

Overcoming obstacles to access to patients' and caregivers' rights

- *Provide patients and caregivers with access to resources that can help them understand the disease and adapt their daily lives by anticipating its impact.*
- *Promote the creation of centres of expertise across all EU Member States, particularly in Member States where none currently exist.*

Recommendations are the result of a structured process based on literature review, (patient) expert workshops in five EU Member States and a developed white paper. Our aspiration is that those recommendations will be the basis for continued discussion, refinement and most importantly – actions at EU and national levels.

First signatories:



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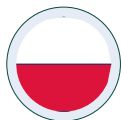
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Together, we can make this happen:

All United For **MG**

All United for MG is a coalition of patient organisations from Belgium, France, Greece, Italy, Poland, Romania and Spain aiming to raise awareness about myasthenia gravis (MG) and its consequences for patients and their caregivers.



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