



European Reference Network

for rare or low prevalence
complex diseases



Network

Neuromuscular
Diseases (ERN EURO-NMD)

Neuromuscular Junction

EURO-NMD Neuromuscular Junction (MG, CMS, etc)

- **“Working Group”**: interest in research from approximately 100 clinicians and scientists across all HCPs
- **PAB**: Marguerite Friconneau (France)
- **Chair**: Hanns Lochmüller (UK)
- **Co-Chairs**: Isabel Illa (Spain); David Beeson (UK); Ulrike Schara (D)



International consensus guidance for management of myasthenia gravis

Executive summary

OPEN 

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ABSTRACT

Objective: To develop formal consensus-based guidance for the management of myasthenia gravis (MG).

Methods: In October 2013, the Myasthenia Gravis Foundation of America appointed a Task Force to develop treatment guidance for MG, and a panel of 15 international experts was convened. The RAND/UCLA appropriateness methodology was used to develop consensus guidance statements. Definitions were developed for goals of treatment, minimal manifestations, remission, ocular MG, impending crisis, crisis, and refractory MG. An in-person panel meeting then determined 7 treatment topics to be addressed. Initial guidance statements were developed from literature summaries. Three rounds of anonymous e-mail votes were used to attain consensus on guidance statements modified on the basis of panel input.

Results: Guidance statements were developed for symptomatic and immunosuppressive treatments, IV immunoglobulin and plasma exchange, management of impending and manifest myasthenic crisis, thymectomy, juvenile MG, MG associated with antibodies to muscle-specific tyrosine kinase, and MG in pregnancy.

Conclusion: This is an international formal consensus of MG experts intended to be a guide for clinicians caring for patients with MG worldwide. *Neurology*® 2016;87:419-425



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Guidelines - Gap analysis

Existing guidelines: MG (mostly adult)

France: 2015, diagnostic protocol for MG (Paris Est)

Germany: 2016, German guidelines (Melzer et al)

Italy: 2017, Recommendations for diagnosis and treatment (Evoli)

UK: 2015, British management guidelines (Sussman et al)

US: 2016, management of MG (Sanders et al)

Catalonia/Spain: management of MG (Illa, Diaz)

Non existing or incomplete guidelines:

Congenital myasthenic syndromes; paediatric MG



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Suggestions for autoimmune MG (Isabel Illa)

1. Guideline of management of MG
2. Registry
3. Antibody testing standardization.

