

Patient organisations ABMM, AIM, AMES, and Liga MG, with the support of argenx, would like to invite you to their online pan-European conference

# Myasthenia Gravis in Europe: an EU perspective

Tuesday, November 29, 2022,  
from 17:30 to 19:00 CET.



[Please click here to register](#)

## ■ Presentation

Myasthenia gravis (MG) is a serious, rare, and chronic neuromuscular autoimmune disease that can cause debilitating and potentially life-threatening muscle weakness. It affects 56,000 to 123,000 people in Europe. On November 29, patients, HCPs and policymakers will discuss the burden of disease in different EU countries and how harmonised and integrated European policies that improve the lives of MG patients and their caregivers can be implemented.

To address these challenges, our patient organisations, supported by argenx, have joined forces to organise a series of patient and caregiver workshops to collect new empirical data on the burden of MG, and to develop new, concrete recommendations on how their needs should be addressed. In the context of current discussions on the need for a coordinated EU rare disease strategy, these recommendations look in particular at how MG could be better incorporated in national rare disease strategies and care pathways, and how European exchanges and collaboration on best-practices could be encouraged to address the substantial differences that remain between EU member states. They also put the focus on the need to better recognise the specific needs of informal caregivers of rare disease patients in light of the Commission's recent EU Care Strategy, which has been proposed to member states.

**To present these findings and recommendations, we warmly invite you to join our online high-level conference on 29 November from 17:00 to 19:30 for a pan-European discussion with patient representatives, senior clinicians, regulators and policymakers – see our programme and registration link below.**



# Programme

## ■ Opening speech

Introduction and presentation of the event by a high-level speaker

## ■ Keynote speech

Presentation on the burden of disease for MG patients, based on exclusive real-world data by Francesco Saccà, Professor in Neurology at the University "Federico II" of Naples

## ■ Roundtable: Myasthenia gravis' impact on patient and caregiver lives: similarities and differences across EU Member States

Discussion between MG patient association representatives and medical experts from different EU Member States such as:

- Belgium: Lutgarde Allard, Board Member of Liga MG, and Jean-Marie Huet, President of ABMM
- Italy: Renato Mantegazza, President of AIM and professor of the Department of Neuroimmunology and Neuromuscular Diseases
- Spain: Raquel Pardo, President of AMES
- Germany: a representative from DMG (to be confirmed)
- France: Béatrice Nectoux, on behalf of the Myasthenia Patient Group of AFM-Téléthon and AMIS

## ■ Roundtable: Shaping harmonised and integrated European policies that improve the lives of MG patients and their caregivers

Discussion between national and European policymakers, MG patient association representatives and medical experts

## ■ Conclusion

Conclusion of the discussion and next steps by Jean-Philippe Plançon, Chairman of EPODIN and Vice-president of Alliances Maladies Rares

[Please click here to register](#)

We would like to inform you that this webinar will be recorded for further dissemination on social networks or within the network of European patient organisations. Therefore, by registering for this event, you consent to be recorded.