

Inspiring Anniversary Highlights

European Patient Advocacy: Uniting Local PAGs To Be Stronger Together

- **More than the sum: Why cross-border European patient advocacy is so vital**

Patients and carers across conditions usually begin their activities locally or nationally. However, international exchange often becomes essential whether because a condition is rare and national efforts lack impact, international research and development are needed, or resources are more available elsewhere

When local groups realize that European unification can benefit all, questions of leadership and governance arise. A common strategy and shared goals become crucial. Coordination and trust-building are key. That's why it's important to bring local groups together and establish efficient communication, exchange, and processes.

We love working with European patient advocacy groups to support their growth.
„Stronger together!“

EUMGS: the first European Myasthenia Gravis Summit



A compelling example of the power of uniting patient groups together was the first European Myasthenia Gravis Summit. For years, regional and national MG patient groups existed, connected at the European level, but true synergies had not been achieved yet.

However, it took a while until **a group of European MG patient advocates was formed** that could take the lead: representatives of national groups, speaking for many others, natural in English, easy with the use of online meeting technology, and equipped with energy and a do-it-mentality.

Those board members of the European umbrella group, **EUMGA**, **worked tirelessly** to make a first in-person members meeting happen, aiming to unite the European MG community, build trust, agree on future strategy, learn from each other, and identify areas where the community is stronger together.

And in November 2024, **MG representatives from 19 countries and 23 organisations** finally gathered in person in Amsterdam!

● **Driving change across borders: A huge success**

The event brought together patient representatives, medical advisors and industry * partners. It was more than a meeting—it was a foundation for future action.

* *The EUMG Summit 2024 was generously supported by Alexion, Argenx, Merck, Johnson&Johnson, Novartis, UCB and NMD Pharma.*

Key Outcomes

- **EUMGA Strategy & Plan 2025:** Unveiled a bold roadmap to tackle unmet needs in MG care, emergency preparedness, and youth advocacy.
- **Scientific Advisory Board (SAB):** Officially introduced and chartered, bringing together globally recognized neurologists and patient advocates to ensure science and lived experience shape future priorities.
- **Interactive workshops with industry:** Spotlighted critical issues such as timely diagnosis, equitable access, and empowering young patients as change agents.
- **Inspiration and innovation:** 19 national MG associations presented their work and inspiring greater collaboration in the future.

“Building a European community simply requires patients wherever they come from to meet each other in person. Although it was our first Summit, we can speak of a great success!

The participants were enthusiastic and their cooperation was an enrichment. Communication and cooperation were strengthened, national projects were discussed, and information was exchanged. Science was given its place in our association thanks to our scientific advisory board, which is composed of neurologists specialized in treatment of MG. In addition, a scientific working group was established, consisting of MG patients with scientific training.

It was a special experience that once again underlined the need for patients and patient representatives to meet, and that these meetings can lead to great achievements.”

- Lut Allard, President of the Board at EUMGA



The first Summit’s goal was to **create a unified European voice for MG patients**. This milestone event signalled a new era: **collaboration without borders, science with empathy, and advocacy with impact**. Since then, communication and exchange among EUMGA members have intensified, EUMGA’s visibility has grown, and the Scientific Advisory Board’s work has advanced. The MG community is now preparing for the next in-person EUMG Summit in Paris in April 2026!

● **SINCE 2016** ●

Why we do what we do at admedicum

At admedicum, we firmly believe that international patient advocacy is a key driver for change. We are proud to support EUMGA and other European and Global patient groups with project management services, contractual assistance, content creation, event moderation and many more activities. For almost 10 years, we have been bringing together people living with chronic and rare diseases, companies, researchers, and healthcare providers – as equals. Only together can we create solutions that truly make a difference.

We are deeply grateful to EUMGA and everyone helping to strengthen the MG community, and we look forward to many more years of exchange, support, and shared learning.

Contact us!

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