The RDCN 2022 Annual Meeting

What is Rare Disease Connect in Neurology (RDCN)?

RDCN is an inclusive educational programme for stakeholders involved in the care management and advancement of MG and other rare neuromuscular conditions. RDCN educational content is led by an external committee of HCPs from the USA, Asia, and Europe.

The ambition of the RDCN programme is to improve evidence-based practices and outcomes for people living with MG, to raise the bar of transformational interprofessional learning, transform interprofessional collaboration, and accelerate the adoption of translational medicine in rare neuromuscular conditions.

In 2022, the RDCN community included over 400 HCPs from 49 countries. Throughout 2022, learning was facilitated via live and digital content culminating in a live educational event in December in Madrid, Spain.

Inspired by Patients, Driven by Science

Henrik Klitgaard, (Former UCB, Belgium).

The 2022 Annual Meeting at a Glance:

- Championing the MG Community
- Management
- Clinical
- Pathogenesis and Diagnosis
- Key Milestones from 2022 for the MG Community

PROs

- Selecting the right PRO

Biomarkers

- miRNA as a biomarker in MG

COVID-19

- MGFA vaccination guidelines

Physical activity in MG

- Potential beneficial effects in MG

Pathogenesis and Diagnosis

Following pathways:

- Navigating the drivers of MG pathogenesis
- Exploring the biological pathways driving MG pathogenesis and how they can be targeted to address underlying pathogenesis of MG.

Jan De Bleecker (Belgium)

MG pathogenesis: What is the role of the thymus?

A deep dive into our understanding of the role of the thymus in MG and how this knowledge could improve future patient outcomes.

Gil Wolfe (USA)

NMJ damage in MG: The point of no return or gateway repair?

A look at the latest research investigating the role of the NMJ in the pathogenesis of MG, and how these insights may help identify novel targets and support an MG diagnosis.

Renato Mantegazza (Italy)

Evidence generation in MG: Trials and tribulations

Considering the challenges faced when generating high-quality evidence in MG and exploring how different study types could address these challenges.

Elena Cortés-Vicente (Spain)

Community Forum

An opportunity for participants to put their questions to the RDCN faculty.

James F. Howard, Jr. (USA)

Jan De Bleecker (Belgium)

Gil Wolfe (USA)

Anna Rostedt Punga (Sweden)

Workshop:

- Shaping the future of patient registries

What factors would you consider when designing an MG registry?

Elena Cortés-Vicente (Spain)

Workshop:

- Dissecting the diagnostic odyssey

What are the barriers to diagnosis?

Michael J. Brouillette (USA)

Case study clinic:

- Live discussion

Discuss the management of complex MG cases with members of the RDCN Steering Committee.

James F. Howard, Jr. (USA)

Nicholas J. Silvestri (USA)

Roman Mantegazza (Italy)

Workshop:

- Collaboration for the MG community:

Addressing patients’ unmet needs

How can we overcome challenges and barriers highlighted by those living with MG?

Vivienne Parry, OBE (UK)

Patient Care

Patient Connect

Discuss the MG lived experience through the eyes of someone living it.

Maya Uccheddu, living with MG (Italy)

What will the management of MG look like for patients in 2042?


Workshop:

- Mission Control: Defining, measuring, and quantifying disease control in MG

What does disease control mean for different patients?

Herz Bi (Canada)

Workshop:

- Multi-disciplinary approach, multiple perspectives

Discover what contribution different specialties can make to the management of MG as part of a multidisciplinary team, and what actions can be taken to deliver an integrated approach to care for those living with MG.

Vivienne Parry, OBE (UK)

Allison Foss (USA)

Pushpa Narayanaswami (USA)

Jade King (UK)

Driving change: Spotlight on patient organisations

Discover the roles and responsibilities of MG patient organisations, focusing on how collaboration between MG patient organisations and MG HCPs can support and advance care for those living with MG.

Vivienne Parry, OBE (UK)

Allison Foss (USA)

Pushpa Narayanaswami (USA)

Workshop:

- Collaboration for the MG community:

Addressing patients’ unmet needs

How can we overcome challenges and barriers highlighted by those living with MG?

Vivienne Parry, OBE (UK)

Championing the MG Community

The 2022 Annual Meeting at a Glance:

Vivienne Parry, OBE (UK)

Collaboration between neurologists, specialist MG nurses, patients, and MG patient organisation representatives.

11 hours of discussion, working sessions, and presentations covering pathogenesis and diagnosis, clinical management, and patient care.

All delivered over 2 days, live in Madrid, Spain.

Looking back over 2022, and into 2023, the community remains at the heart of RDCN.

We look forward to continuing the RDCN journey through 2024 and beyond!