The RDCN 2022 Annual Meeting

Rare Disease Connect in Neurology

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.

Vivienne Parry, OBE (UK)

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), Vivienne Parry, OBE (UK)

> **"Be daring … if you're not daring, you are not going to innovate. Period!"**
> *Henrik Klitgaard, (Former UCB, Belgium)*

Key Milestones from 2022 for the MG Community

Gil Wolfe (USA), Anna Rostedt Punga (Sweden)

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 potential for 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)

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), Renato Mantegazza (Italy), Anna Rostedt Punga (Sweden)

Workshop: Dissecting the diagnostic odyssey
What are the barriers to diagnosis?
Nicholas J. Silvestri (USA)

Read the summary of the workshop discussion on the RDCN website.

Clinical Management

What will the management of MG look like for patients in 2042?
Wearables? Artificial intelligence? Big data? Digital twins? Cell-based therapy? Nano technology?
Henry J. Kaminski (USA)

Workshop: Mission Control: Defining, measuring, and quantifying disease control in MG
What does disease control mean for different patients?
Vera Bril (Canada)

Read the summary of the workshop discussion on the RDCN website.

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.
Pushpa Narayanaswami (USA), Elena Cortés-Vicente (Spain), Kimiaki Utsugisawa (Japan)

Workshop: Shaping the future of patient registries
What factors would you consider when designing an MG registry?
Elena Cortés-Vicente (Spain)

Read the summary of the workshop discussion on the RDCN website.

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), Renato Mantegazza (Italy), Pushpa Narayanaswami (USA)

Patient Care

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

> **"Physicians can't treat MG by the book."**
> *Maya Uccheddu (Italy)*

Maya Uccheddu, living with MG, (Italy), James F. Howard, Jr. (USA)

Multidisciplinary approach, multiple perspectives
Discover what contribution different specialities 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), Jude Kings (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), Lut Allard (Belgium), Matthieu Lusignan (France)

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)

Read the summary of the workshop discussion on the RDCN website.

Championing the MG Community

The 2022 Annual Meeting at a Glance:
Vivienne Parry, OBE (UK), Donatello Crocetta (UCB, Belgium)

6
Steering Committee members

>15
faculty members

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!

For more information on the RDCN 2022 annual meeting, visit the RDCN website
This website is intended for HCPs with a special interest in MG only