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Burden of Disease in Multifocal Motor Neuropathy: A Global Quantitative Survey of Patients

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BACKGROUND

MMN

- MMN is a rare, immune-mediated, complement-driven chronic neuropathy leading to axonal degeneration and progressive, disabling, asymmetric limb weakness with an absence of sensory loss[1–3]
- Immunoglobulins are the current standard of care in MMN;[1,4] however, ~90% of patients continue to experience axonal degeneration, despite maintenance treatment and dose increases[2,5,6]
- IVIg requires frequent infusions, can be associated with adverse events, is expensive, and may be subject to availability issues[6,7]
- Patients living with MMN report broad impacts of MMN and its treatment on their daily lives, work, social life, and overall well-being[8]
- We report results from a quantitative, 15-minute, 53-item online survey of patients with MMN, with the aim of:
  - Understanding the physical, emotional, and socioeconomic impact of MMN on patients' lives
  - Providing health care professionals, policy makers, and patient advocacy groups with insights into improving the diagnosis, treatment, and support systems for individuals living with MMN

STUDY DESIGN AND PARTICIPANTS

Study Design

- Participants were recruited from around the world through the GBS/CIDP Foundation International
- Criteria for participation included:
  - Adults aged 18 years or older
  - Diagnosed with MMN by a healthcare provider
  - Lived in their current country of residence for ≥6 months
- Data collection began in July 2024 and is ongoing
- As of October 31, 2024, 55 patients participated. Interim results are presented

Country	Participants, n (%)
TOTAL	**55 (100.0)**
United States	43 (78.2)
Canada	6 (10.9)
Australia	2 (3.6)
New Zealand	2 (3.6)
Norway	1 (1.8)
Austria	1 (1.8)

RESULTS

Average years between symptom onset and diagnosis:

6 years

Reported misdiagnosis was common:

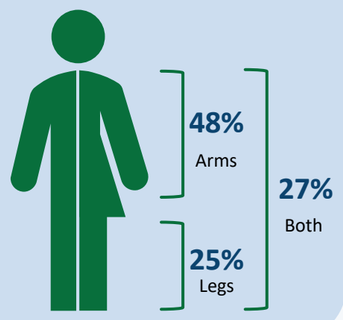
Initial Diagnosis	Patients (n=55)
MMN	29%
ALS	25%
Compression neuropathies*	25%
Peripheral neuropathy	13%
CIDP	11%
Muscle disorder†	7%
GBS	4%
Other	13%

History of Diagnosis

First Symptoms of MMN

- 80% Muscle weakness
- 64% Muscle twitching
- 53% Muscle cramps
- 20% Sensitivity to temperature changes
- 16% Sudden, sharp, shooting pains resembling electric shocks

Where Muscle Weakness Was First Experienced



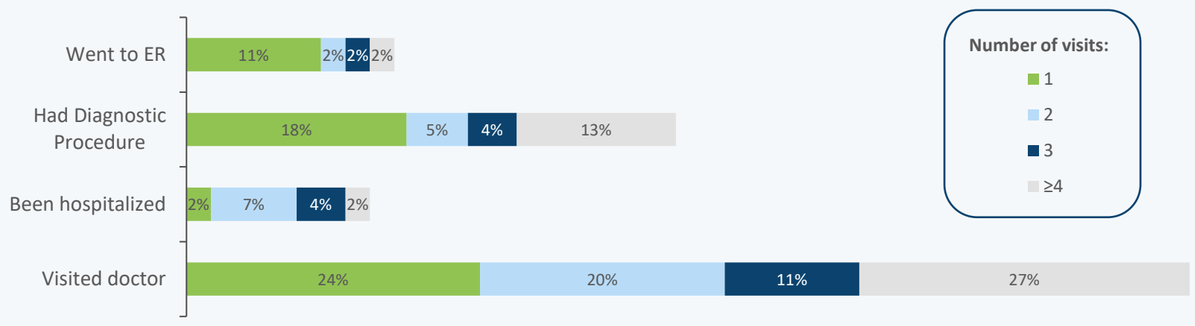
Diagnostic Tests‡

- 89% Electromyography
- 84% Nerve conduction studies
- 84% Anti-GM1 antibody testing (blood test)
- 73% MRI scan
- 35% Lumbar puncture

*Including carpal tunnel syndrome or ulnar neuropathy. †Including myasthenia gravis or muscular dystrophy. ‡Patients were asked to rank all diagnostic tests/procedures they received to diagnose MMN. Electromyography and nerve conduction studies were listed as individual diagnostic procedures and are presented here as such.

Treatment Experience

- In the year before completing the survey:
  - Patients visited a doctor 4 times on average and had 2 diagnostic procedures
  - An average 17% of patients visited the ER and 15% were hospitalized



- Since diagnosis, 56% of patients have received only 1 type of treatment
- IVIg is the current treatment for 69% of patients

Patients receiving IVIg

- **63%** Two-thirds of patients receive treatment at home
- **70%** 70% of patients receive an Ig infusion every 2–4 weeks
- **76%** For most patients, each infusion lasts ≥3 hours
- **59%** Most patients see symptom improvement within 1 week

Impact of MMN Treatment and Symptoms

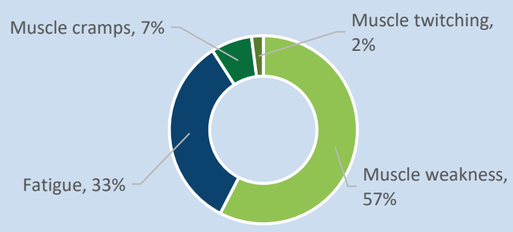
Treatment Side Effects

- 76% of patients feel the treatment side effects impact their work outside and inside the home
- 24% of patients switched MMN therapy due to side effects
- 22% of patients found side effects to be the most difficult aspect of their current MMN treatment

Most Common Side Effects of MMN Treatment	Total (n=55)
Headaches	75%
Feeling tired or lethargic	62%
Fever, chills, body aches, and fatigue	40%
Muscle weakness	27%
Feeling dizzy or lightheaded upon standing or changing positions	25%

Impact of MMN Symptoms on Work and QoL

Symptoms Most Impacting Work



- Most patients (95%) reported their symptoms interfered with their work
- 63% of patients felt the impact on the ability to work was 'little' to 'moderate'; 31% felt the impact was 'quite a lot' or 'extreme'

Work Productivity

- 60% of patients missed workdays; the average number of days missed in the past year was 87.2
- 87% of working patients felt their symptoms impacted their productivity; 17% of patients felt their symptoms 'prevented' or 'nearly completely prevented' their productivity
- 13% and 9% of patients felt their condition prevented them from working either full-time or part-time, respectively

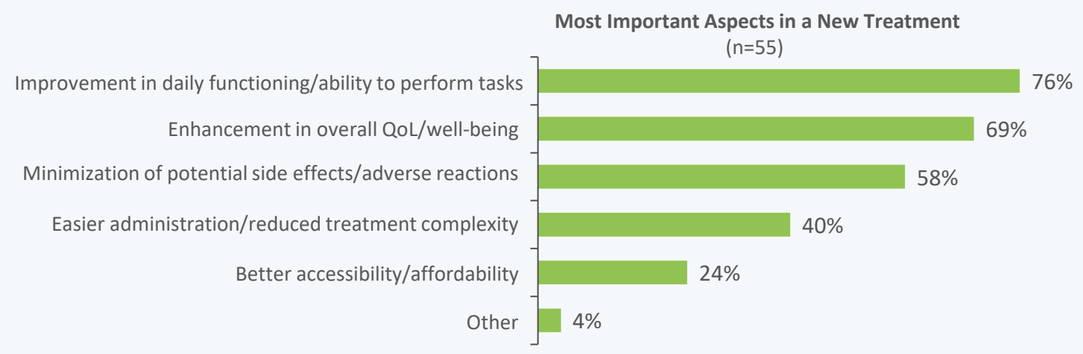
Social Activity

- Symptoms prevented social and regular activity participation in 64% and 27% of patients, respectively
- In the past year, patients missed an average 70.3 days of social activity

Features of New MMN Treatments: A Patient Perspective

Aspects Patients Want to Change About Their MMN Situation:

A cure to be found · Decrease in treatment duration · Earlier diagnosis · Reduction in muscle loss · Increase in mobility and control



KEY TAKEAWAYS

- Patients with MMN experience significant challenges to work, social activities, and QoL due to their symptoms
- MMN has a significant impact on patient productivity
- Survey results provide valuable insights into improving diagnosis, treatment, and support systems for patients with MMN
- Study recruitment is ongoing

SCAN ME
To join the study

Presented at the 2025 Peripheral Nerve Society (PNS) Annual Meeting; May 17–20, 2025; Edinburgh, UK

ABBREVIATIONS

ALS, amyotrophic lateral sclerosis; CIDP, chronic inflammatory demyelinating polyneuropathy; ER, emergency room; GBS, Guillain-Barré syndrome; GM1, monosialotetrahexosylganglioside; Ig, immunoglobulin; IVIg, intravenour Ig; MMN, multifocal motor neuropathy; MRI, magnetic resonance imaging; QoL, quality of life.

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