



Global MMN Quality of Life Patient Survey  
Identifies Needs in Education and  
Treatment

# Disclosure

- The presentation contains information outside the labelled indication for subcutaneous immunoglobulin (SCIG)

1. First Global Multifocal Motor Neuropathy (MMN) Quality of Life (QOL) Patient Survey Identifies Needs in Education and Treatment. Available at [http://www.neuropathyaction.org/downloads/MMN\\_article%209-26-2016.pdf](http://www.neuropathyaction.org/downloads/MMN_article%209-26-2016.pdf). Accessed March 2017.
2. Leger, JM. Clin Exp Immunol. 2014; 178 Suppl 1:42-4.

# MMN patient survey: Background & objectives (I)

- Multifocal Motor Neuropathy (MMN) is a rare condition whereby the immune system attacks multiple motor nerves<sup>1</sup>
  - Results in progressive muscle wasting and weakness
  - Affects 0.6 in 100,000 individuals worldwide
  - Linked to motor dysfunction and moderate-to-severe disability
- IVIG is the preferred first-line treatment owing to its safety profile and beneficial effect on muscle strength and disability<sup>2</sup>

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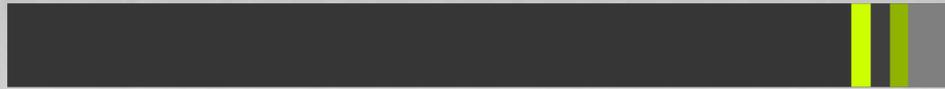
## MMN patient survey: Background & objectives (II)

- The Neuropathy Action Foundation conducted the first global MMN quality of life (QoL) survey to:<sup>1</sup>
  - Identify gaps in education or treatment
  - Help patients gain control of their condition and take ownership of their care
- The survey was completed by 211 individuals based in 24 countries around the world, although the majority of respondents (>70%) were from the United States
- Survey respondents were evenly split between men and women (47% vs. 53%, respectively) despite the higher reported incidence of MMN in men

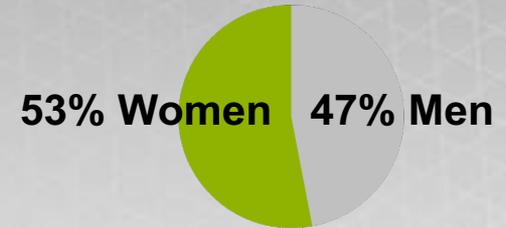
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# MMN patient survey: Demographics<sup>1</sup>

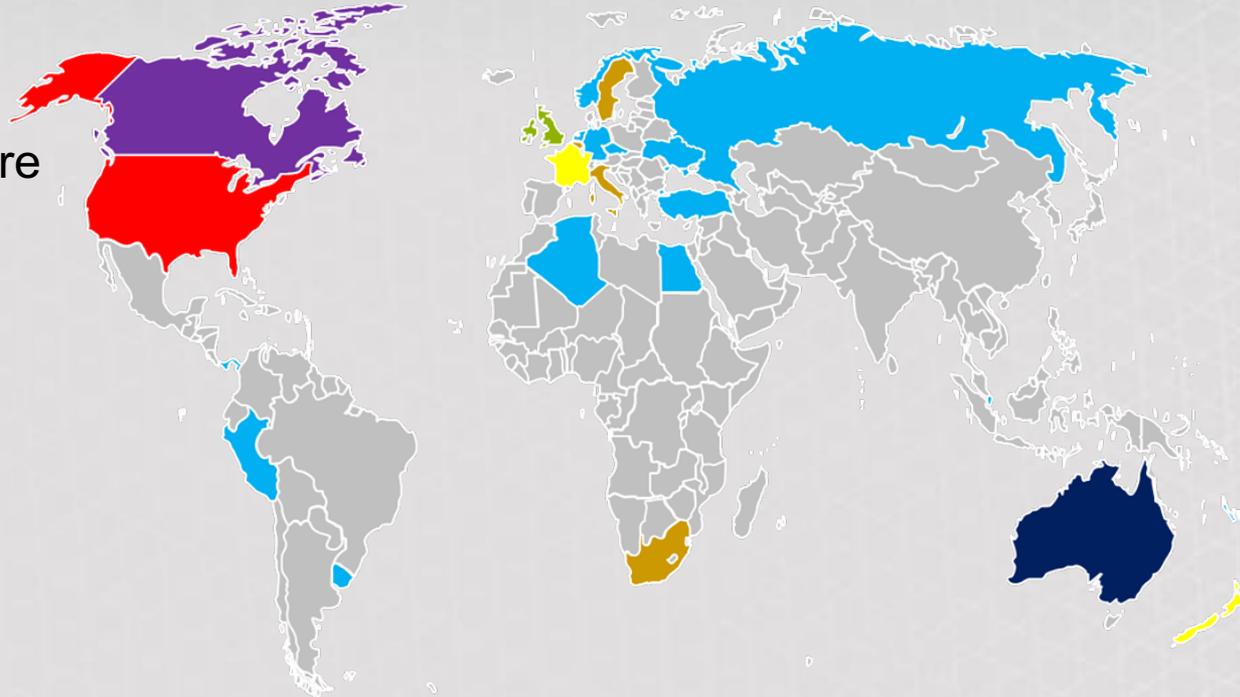
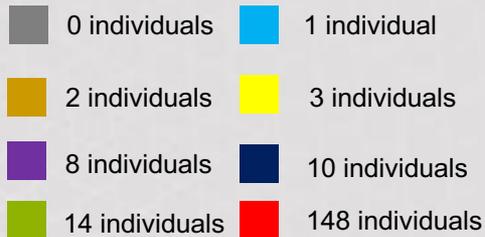
- 211 survey participants



- Caucasian - 89%
- African American - 2%
- Asian/Pacific Islander - 2%
- Hispanic - 2%
- Other - 5%



- Most respondents were from the US
  - Texas, Florida, California, Illinois



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# MMN diagnosis (I)<sup>1</sup>

- The diagnosis of MMN is based on motor symptoms and signs
- MMN may only affect a single nerve and cause weakness in one limb
- It can also cause more generalized weakness
- MMN typically develops asymmetrically
- The electrophysiological hallmark of the disorder is the diagnosis of “conduction block”

Failure to recognize conduction block can contribute to misdiagnosis

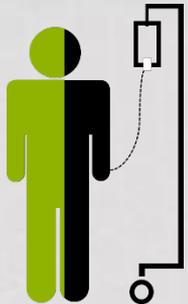
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## MMN diagnosis (II)

Men are more likely to be affected by MMN than women in a ratio of 2.7:1<sup>1</sup>

Weakness most commonly develops in the forearm and hand muscles<sup>1</sup>

Weakness may also occur in the distal leg and upper arm<sup>1</sup>



**57%** of patients diagnosed between the ages of 41 and 65 years<sup>2</sup>



**67%** required more than 1 year to be diagnosed<sup>2</sup>

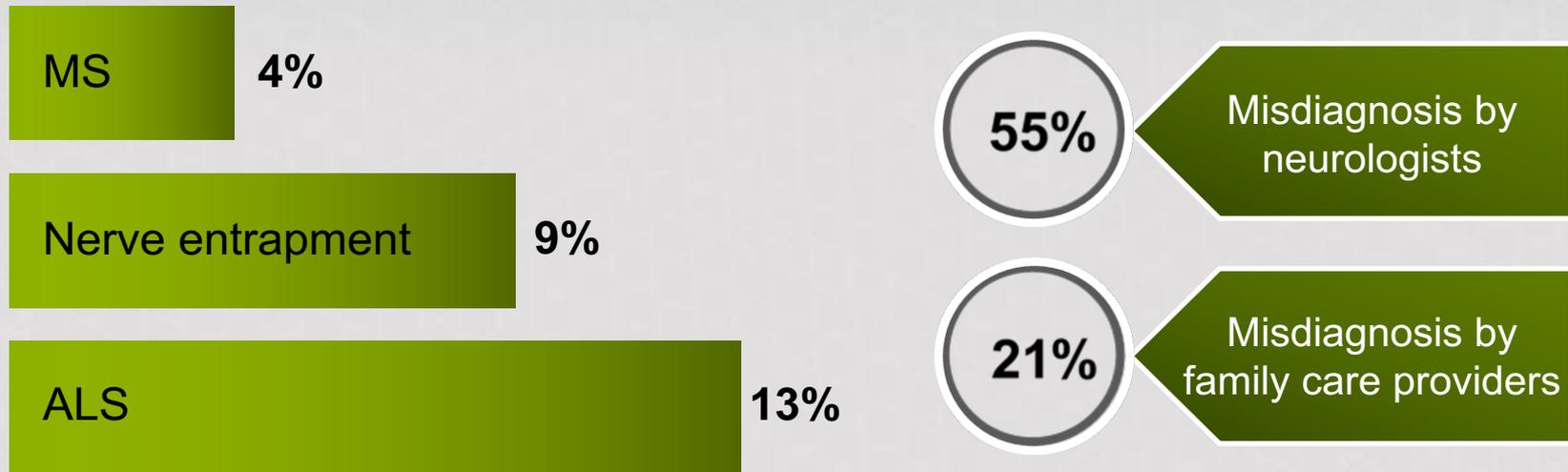
**44%** required 2–3 years to be accurately diagnosed<sup>2</sup>

1. Van den Berg, LH. Eur Neurol Rev. 2012;7(2):128-133

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# MMN misdiagnosis<sup>1</sup>

- MMN only affects motor nerves and therefore often results in symptoms that mimic other conditions
  - Some patients were told they were suffering from hysteria, too much caffeine, menopause, old age, or were not given a diagnosis at all

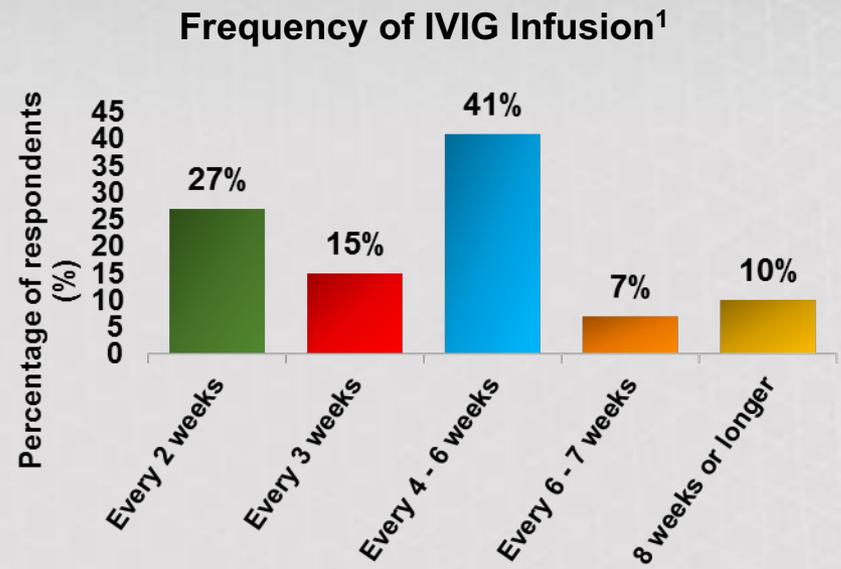
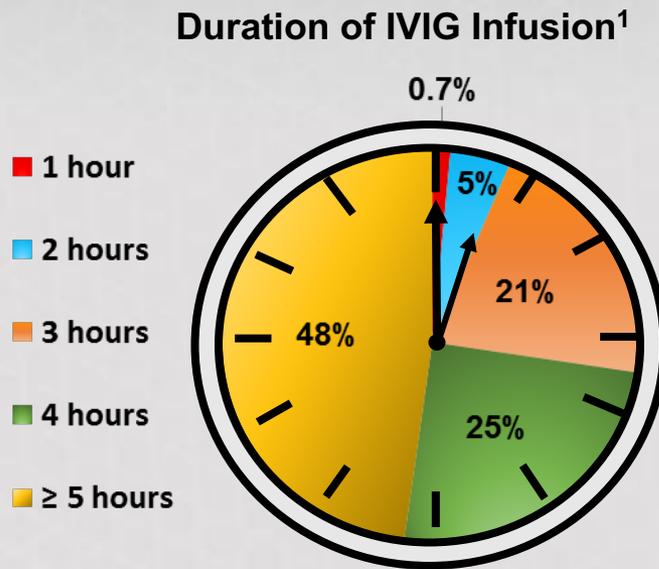


ALS: amyotrophic lateral sclerosis; MS: multiple sclerosis

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# MMN treatment

- Majority of respondents reported receiving IVIG therapy (91%); the remainder (9%) reported receiving SCIG<sup>1</sup>
- 81% would consider SCIG therapy if recommended by a neurologist,<sup>1</sup> and it is sometimes preferred to IVIG<sup>2</sup>



Duration of treatment can add to the burden of MMN

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# Treatment access

36% Access issues to IVIG therapy<sup>1</sup>

17% Forced to switch medication brands<sup>1</sup>



18% unable to afford therapy at some point



DENIALS



IVIG THERAPY

“not medically necessary”



PORTABILITY



Transitioning between insurance providers causing lapses or delays in therapy

IVIG is well tolerated when used as maintenance treatment

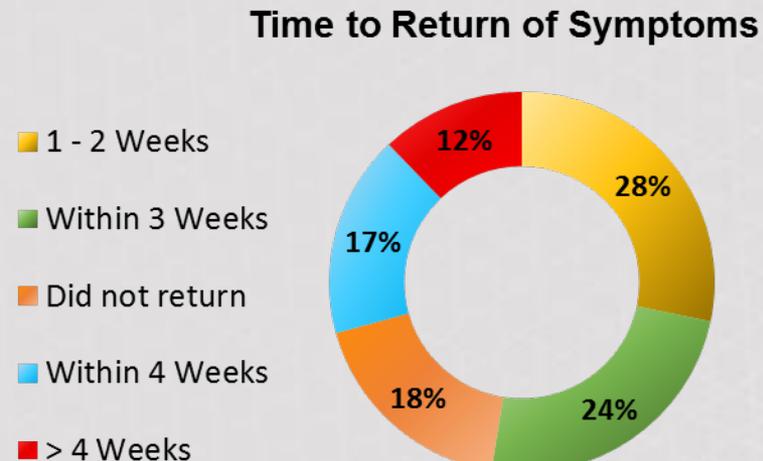
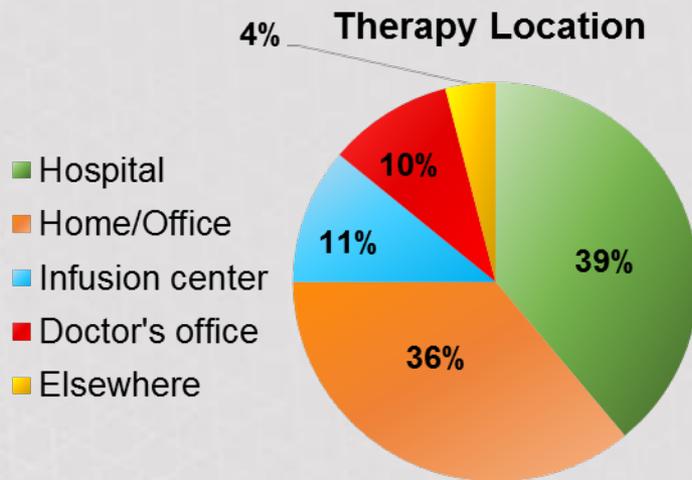
Continuous monitoring of patients is necessary as most patients require increased dose or higher frequency of infusion to maintain treatment response<sup>2</sup>

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# Symptoms & treatment location

- 36% reported reduction in symptoms within one week of the initial IgG treatment
  - Improvements following IVIG therapy included **feeling stronger, improved balance, and less cramping and pain**<sup>1</sup>
- Patients were concerned about difficulties in finding local infusion centers<sup>1</sup>
- Home IVIG infusion is preferred by patients, is cost-saving and maintains patients' function as effectively as hospital treatment<sup>2</sup>



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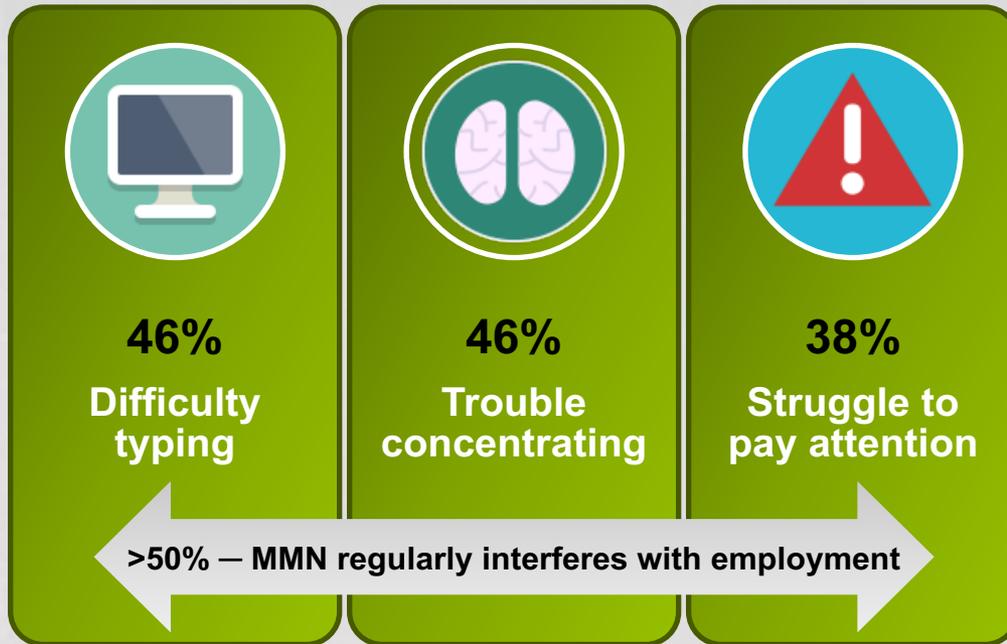
# Commonly reported symptoms and signs<sup>1</sup>

- 52% of survey respondents reported that they had conduction block
- Commonly reported physical findings included:
  - Upper body weakness (49.5%)
  - Lower body weakness (47.5%)
  - Finger or foot drop (11%)
  - Numbness (10%)
  - Pain (10%)
  - Muscle cramps (9%)

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# Social activities & employment among MMN patients<sup>1</sup>

- Participants reported that MMN significantly impacts their life and restricts their social activities
  - 75% reported having no energy
  - 78% reported experiencing daytime sleepiness



**45%** of respondents avoided or cancelled activities with friends and family

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# Impact on daily tasks<sup>1</sup>



**62%** too tired to do **household chores**



**46%** had difficulty **buttoning shirt**



**58%** struggled or failed to **open a medicine bottle**



**48%** had difficulty **turning a key in a lock**



**36%** struggled to **stand for a period of time**



**51%** struggled or failed to **walk for 15 mins**

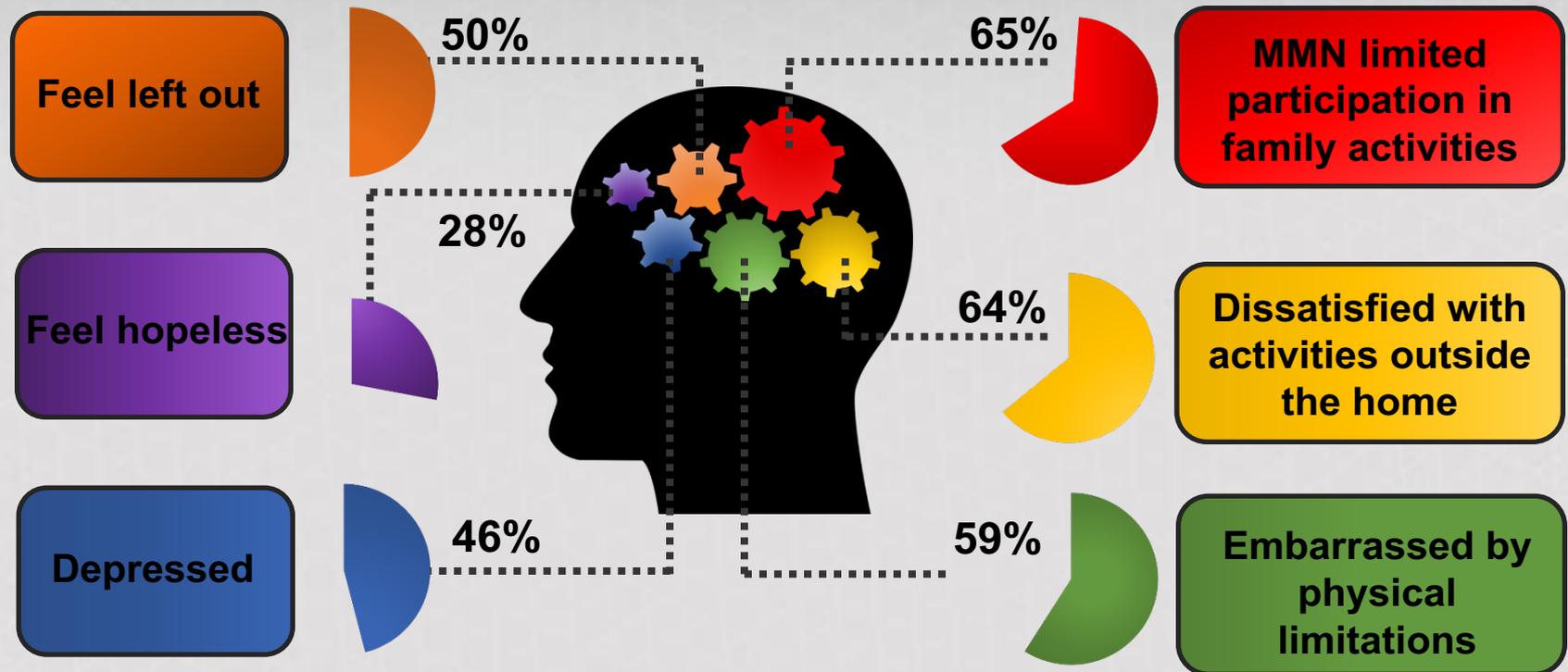


**53%** struggled or failed to **walk up and down a flight of stairs**

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# Impact on emotional wellbeing<sup>1</sup>

MMN patients reported restrictions in activities and a negative effect on emotional wellbeing



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# MMN patient survey: Conclusions<sup>1</sup>

- The survey highlighted important factors regarding the landscape of diagnosis and management, as well as the QoL experience of patients with MMN
- Patients are grateful that MMN is being researched and studied
  - Some patients are empowered and knowledgeable about their condition
  - Other patients believe that it is difficult to find information about the condition
- Further efforts are required to educate patients, physicians, and insurers in order to improve diagnosis and management of MMN

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