Ignition Survey Results: Fatigue in MOGAD

Brought to you by The MOG Project in collaboration with MyMyelitis

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Demographics of Respondents

115/187 (62%) of MOG Positive Patients and 50/62 (81%) Members Of Their Household Who Don’t Have MOGAD are primarily located in the ‘United States of America’.

There were more females than males seen in both MOG Positive Patients and Members Of Their Household Who Don’t Have MOGAD.

Majority of respondents’ Ethnic background were predominantly ‘White or Caucasian’ Making up 154/187 (82%) of MOG Positive Patients and (50/62) 81% of Members Of Their Household Who Don’t Have MOGAD. However, it is clear that MOG Antibody Disease (MOGAD) is not biased to race or ethnicity, as the disorder can present in other Ethnic Backgrounds seen in this table.

All numbers have been rounded off to the nearest percentage (%).
Fatigue is defined as a subjective lack of physical or mental energy perceived by the individual with usual activities. MFIS is a patient-reported outcome (a questionnaire) and has 21 items (questions). The scale score is the sum of the 21 items, and a higher score indicates more severe fatigue. The minimum score is 0 and the maximum score is 84. It also has three sub-scores: physical, cognitive, and psycho-social fatigue.

When we looked at the total MEDIAN (MED) Modified Fatigue Impact Scale (MFIS) Score of the overall participants who responded to both surveys, it was evident that MOG Positive Adult Females >18 suffered the most amount of fatigue, as their total MED MFIS Score was 51.5 followed by MOG Positive Adult Men >18 with a MED MFIS Score of 50. MOG Positive Pediatrics <18 had a total MED MFIS Score of 36 which was equivalent to the total MED MFIS Score of Female Adult Members Of Their Household Who Don’t have MOGAD. Surprisingly, when you look at the data individually, Men between the ages of 45-54 suffered the most fatigue with the highest MED MFIS Score of 69.5, followed by Female Adult Members Of Their Household Who Don’t have MOGAD between the ages 18-24 with a MED MFIS Score of 57.

Please note that this data was represented based on the opinion and ratings of the respondents.
Diagnosis of MOG Antibody Disease (MOGAD)

Estimated Diagnosis vs Official Diagnosis

**Estimated MOGAD diagnosis prior to the official MOGAD diagnosis**

- <1 year: 15%
- 1-2 years: 25%
- 6-9 years: 13%
- 10-15 years: 12%
- 16-20 years: 5%
- >20 years: 8%

**Number of years officially diagnosed with MOGAD**

- <1 year: 32%
- 1-2 years: 35%
- 3-4 years: 23%
- >5 years: 10%

187/187 MOG Positive Patients responded to this question.

In their opinion, one in four respondents (25%) estimated that they’ve had MOG Antibody Disease (MOGAD) for ‘1-2 years’. 42/187 (22%) think they’ve had MOGAD for ‘3-5 years’ whilst 28/187 (15%) estimated ‘<1 year’ for their diagnosis.

186/187 MOG Positive Patients responded to this question.

66/186 (35%) of respondents were officially diagnosed with MOG Antibody Disease (MOGAD) in the last ‘1-2 years’. 59/186 (32%) have had MOGAD for ‘<1 year’ whilst 42/186 (23%) were diagnosed ‘3-4 years’ ago.
CNS Presentations of Respondents With MOGAD

**MOG Positive Pediatrics <18**
(N=21)

- **Encephalitis, 15%**
- **Unilateral Optic Neuritis (UON), 11%**
- **Bilateral Optic Neuritis (BON), 20%**
- **Brainstem, 13%**
- **Acute Disseminated Encephalomyelitis (ADEM), 28%**
- **Other/Unsure, 2%**
- **Transverse Myelitis (TM), 11%**

21 MOG Positive Pediatrics <18 responded to this question.

In this group, 13 (28%) experienced ‘Acute Disseminated Encephalomyelitis (ADEM)’ as a CNS presentation at some point in their disease, making it the dominant phenotype in MOG Positive Pediatrics. 9 (20%) had ‘Bilateral Optic Neuritis (BON)’ and 7 (15%) experienced ‘Encephalitis’.

**MOG Positive Adults >18**
(N=166)

- **Unilateral Optic Neuritis (UON), 22%**
- **Bilateral Optic Neuritis (BON), 24%**
- **Brainstem, 11%**
- **Transverse Myelitis (TM), 20%**
- **Other/Unsure, 9%**
- **Encephalitis, 6%**
- **Unilateral Optic Neuritis (UON), 24%**

166 MOG Positive Adults >18 responded to this question.

In this group, 73 (24%) experienced ‘Bilateral Optic Neuritis (BON)’ as a CNS presentation at some point in their disease whilst 69 (22%) had ‘Unilateral Optic Neuritis (UON)’. Optic Neuritis was the dominant phenotype in MOG Positive Adults making a combined total of (46%) of the overall presentations, whilst 63 (20%) experienced ‘Transverse Myelitis’.

A tally was given to each CNS presentation that the respondents have experienced throughout the course of their MOG Antibody-Disease.
Treatments Currently Being Used for MOGAD in This Group

**Acute treatment(s)** in MOG Antibody Disease are used in short-term circumstances to treat an acute attack or relapse happening in the Central Nervous System (CNS) at present.

109/187 MOG Positive Patients are not taking any Acute treatment(s) ‘N/A’. 34/187 are currently taking ‘Intravenous Immunoglobulin (IVIG)’, followed by ‘Oral Prednisolone (OP)’ 33/187 as an Acute treatment.

**Preventative treatment(s)** in MOG Antibody Disease are used as a long-term therapy to suppress the immune system and prevent further CNS demyelinating attacks known as ‘relapses’ or ‘flares’.

50/187 MOG Positive Patients are currently taking ‘Rituximab (Rituxan)’ as a Preventative treatment. 43/187 are on ‘Intravenous Immunoglobulin (IVIG)’ whilst 36/187 are currently not on any treatment (No Treatment).

A tally was given to each Acute treatment and Preventative treatment option even if they were taken in combination with another treatment.

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Responses to Fatigue by Physician(s)

Have you brought up concerns about fatigue to the Physician(s) who treats you for MOGAD?

- Yes: 65%
- No: 18%
- Not yet: 17%

176/187 MOG Positive Patients responded to this question. 115/176 (65%) answered ‘Yes’, bringing concerns about fatigue to their Physician(s) who treats them for their MOG Antibody Disease. 31/176 (18%) have not brought up fatigue to their doctor(s) answering ‘No’.

How concerned was your Physician when you brought up your fatigue?

- 1 (Not at all concerned): 18%
- 2: 20%
- 3: 11%
- 4: 5%
- 5 (Very concerned): 18%
- I haven't asked: 25%
- Not sure: 4%

165/187 MOG Positive Patients responded to this question. 41/165 (25%) ‘Haven't asked’ their Physician who treats them for their MOG Antibody Disease. In their opinion, 33/165 (20%) answered ‘2’ on the Concerned Physician fatigue scale and 29/165 (17%) answered ‘1 Not at all concerned.’

The Concerned Physician Fatigue Scale has been ranked from 1-5. 1 being ‘Not at all concerned’ and 5 being ‘Very concerned’.

Please note that these responses are based on the opinion of the respondents.
Other Medical Diagnosis

In both groups, ‘Low Vitamin D <50’ was the most common diagnosis and was seen in 69/187 (37%) of the MOG Positive Patients and 26/62 (26%) of Members Of Their Household Who Don’t Have MOGAD. 31/187 (17%) of MOG Positive Patients and 9/62 (15%) Members Of Their Household Who Don’t Have MOGAD have ‘High Blood Pressure’. ‘Other Autoimmune Diseases’ were noted in 24/187 (15%) of MOG Positive Patients and 4/62 (6%) in Members Of Their Household Who Don’t Have MOGAD.

56/187 (30%) of MOG Positive Patients and 23/62 (37%) Members Of Their Household Who Don’t Have MOGAD did not have any other medical conditions ‘N/A’.

All numbers have been rounded off to the nearest percentage (%).
Signs and Symptoms Exhibited by Respondents

In their opinion, the most common symptom experienced in MOG Positive Patients were Headaches’ 138/187 (74%), followed by ‘Problems thinking, remembering or concentrating’ 137/187 (73%).

Whereas 38/62 (59%) of Members Of Their Household Who Don’t Have MOGAD experienced Muscle or joint pain’, followed by ‘Sleep problems, such as insomnia’ 33/62 (52%).

All numbers have been rounded off to the nearest percentage (%).
Fatigue Experiences in MOGAD Respondents

21 MOG Positive Pediatrics responded to this question.

166 MOG Positive Adults responded to this question.

In their opinion, the most common fatigue experienced in MOG Positive Pediatrics was ‘Emotional Fatigue’ 14/21 (67%), followed closely by ‘Physical Fatigue’ 13/21 (62%).

Whereas in MOG Positive Adults, the most common fatigue experienced in their opinion was ‘Physical Fatigue’ 143/166 (86%), whilst 117/166 (70%) suffered from ‘Mental Fatigue’.

75/187 (45%) of MOG Positive Adults were more likely to experience ‘Pain Fatigue’ in comparison to MOG Positive Pediatrics 3/21(14%).

All numbers have been rounded off to the nearest percentage (%).
187/187 MOG Positive Patients responded to this question.

In their opinion, 153/187 (82%) ‘currently feel fatigued or tired often’, 25/187 (13%) have not felt fatigued or tired currently, but have in the past and 9/187 (5%) have never felt fatigued or tired often.

When we compared the fatigue outcomes of those who have MOG Antibody Disease to their current treatment status, it was evident that those who are currently on Preventative treatment were more likely to be ‘fatigued or tired often’ 131/154 (85%) compared to 22/154 (14%) who were ‘Fatigue and tired often’ but were not on any treatment.

16/31 (52%) who were on Preventative treatment, ‘do not currently feel fatigued or tired often, but have in the past’ compared to 7/31 (22%) who are currently on Acute treatment. However, 6/12 (50%) who are on Preventative treatment ‘do not currently feel fatigued or tired often, and have not in the past’.

All numbers have been rounded off to the nearest percentage (%). Please note that a tally was given to each Acute treatment and Preventative treatment option even if they were taken simultaneously.
Fatigue and MOGAD Relapses
Pseudo-Relapses vs Relapses

In their opinion, (31%) of both MOG Positive Pediatrics 5/16 and Adults 49/159 felt that their fatigue was 'Sometimes' related to their MOGAD pseudo-relapses. 4/16 (25%) of MOG Positive Pediatrics and 47/159 (30%) of MOG Positive Adults affiliated their pseudo-relapses as 'Often' being associated with their fatigue. Surprisingly, 50/159 (31%) of MOG Positive Adults felt that they were 'Unsure'.

A MOGAD pseudo-relapse is the recurrence of neurological symptoms often due to an exacerbating factor or trigger such as heat, stress, sickness or exercise which tends to improve over 24-48 hours.

In their opinion, 5/16 (31%) of MOG Positive Pediatrics felt that their fatigue was ‘Sometimes’ related to their MOGAD relapses compared to 67/160 (29%) of MOG Positive Adults. 4/16 (25%) MOG Positive Pediatrics were ‘Unsure’ compared to 67/160 (42%) of MOG Positive Adults.

A MOGAD relapse is when a patient presents to their doctor or hospital with new or worsening central nervous system (CNS) symptoms that gradually worsen >24 hours. Relapses are also sometimes referred to as ‘flares’ by the MOGAD community.

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All numbers have been rounded off to the nearest percentage (%).
Fatigue and Medication(s)

150/166 MOG Positive Adults responded to the first question and 159/166 responded to the second question. In their opinion, 53/150 patients (36%) agree that their fatigue is ‘5 Completely related’ to MOGAD itself and not the medication(s) that they are taking. 50/159 (31%) of adults think that their fatigue is ‘1 Not at all related’ to their medication(s) that they are taking for MOGAD.

15/21 MOG Positive Pediatrics responded to both questions. In their opinion, 5/15 patients (40%) agree that their fatigue is ‘5 Completely related’ to MOGAD itself and not the medication(s) that they are taking. One out of 3 pediatrics (33%) think that their fatigue is ‘1 Not at all related’ to their medication(s) that they are taking for MOGAD.

All numbers have been rounded off to the nearest percentage (%).
Sleep Patterns and Difficulties

**MOG Positive Pediatrics (N=20)**
- **Never**: 25%
- **Sometimes**: 50%
- **Often**: 20%
- **Nearly every night**: 0%
- **Unsure**: 5%

In their opinion, 10/20 (50%) have troubles sleeping ‘Sometimes’ and 5/20 (25%) ‘Never’ have difficulties sleeping.

**MOG Positive Adults (N=166)**
- **Never**: 13%
- **Sometimes**: 29%
- **Often**: 25%
- **Nearly every night**: 32%
- **Unsure**: 1%

In their opinion, 53/166 (32%) have problems sleeping ‘Nearly Every Night’ and 48/166 (29%) have difficulties sleeping ‘Sometimes’.

**Members Of Their Household Who Don't Have MOGAD (N=61)**
- **Never**: 5%
- **Sometimes**: 46%
- **Often**: 26%
- **Nearly every night**: 21%
- **Unsure**: 2%

In their opinion, 28/61 (46%) have difficulties sleeping ‘Sometimes’ and 16/61 (26%) have troubles sleeping ‘Often’.

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Fatigue and Sleep

ON AVERAGE, HOW MANY HOURS OF INTERRUPTED SLEEP DO YOU GET EACH NIGHT?

- **MOG Positive Pediatrics (N=20):**
  - <5 hours: 15% (37% reported 39%)
  - 5-6 hours: 25% (39% reported 39%)
  - 7-8 hours: 30% (21% reported 29%)
  - >9 hours: 30% (25% reported 29%)

- **MOG Positive Adults (N=166):**
  - <5 hours: 25% (39% reported 39%)
  - 5-6 hours: 29% (37% reported 37%)
  - 7-8 hours: 30% (21% reported 21%)
  - >9 hours: 30% (22% reported 22%)

- **Members Of Their Household Who Don’t Have MOGAD (N=61):**
  - <5 hours: 30% (7% reported 7%)
  - 5-6 hours: 30% (7% reported 7%)
  - 7-8 hours: 25% (7% reported 7%)
  - >9 hours: 30% (7% reported 7%)

In their opinion, 6/20 (35%) MOG Positive Pediatrics slept for at least ‘7-8 hours’ or ‘>9 hours’. 65/166 (39%) MOG Positive Adults slept for an average of ‘5-6 hours’ whereas 62/166 (37%) slept for ‘<5 hours’. 24/62 (39%) Members Of Their Household Who Don’t Have MOGAD slept for an average of ‘<5 hours’ whilst 18/61 (29%) slept for ‘5-6 hours’. 7/20 (35%) MOG Positive Pediatrics woke up ‘0’ or once ‘1’ during the night, 44/166 (27%) of MOG Positive Adults woke up at least ‘3’ times whilst 43/166 (26%) woke up at least twice ‘2’ whilst 16/61 (26%) woke up once ‘1’.

In comparison to the average amount of sleep they were getting each night to the average amount of times they were waking up, MOG Positive Pediatrics had favourable outcomes, sleeping for more than >7 hours and only waking up 0-1 times during the night. MOG Positive Adults’ sleep was interrupted, averaging <6 hours of sleep every night whilst waking up 2-3 times. Members Of Their Household Who Don’t Have MOGAD slept for <6 hours and waking up at least 1-2 times.

All numbers have been rounded off to the nearest percentage (%).
16/21 MOG Positive Pediatrics responded to this question.

In their opinion, 7/16 (44%) MOG Positive Pediatrics rated a ‘2’ on the scale, not relating their fatigue to the amount of sleep they get each night compared to 25/159 (22%) of MOG Positive Adults.

4/16 (25%) of MOG Positive Pediatrics agreed that their fatigue was ‘1 Not at all related’ to the amount of continuity of sleep they were getting each night, whilst 56/159 (35%) MOG Positive Adults agreed that it was somewhat related, rating a ‘3’ on the scale.

This indicates that MOG Positive Adults are somewhat likely to attribute their fatigue to the amount of continuity of sleep they are receiving each night compared to MOG Positive Pediatrics.

All numbers have been rounded off to the nearest percentage (%).
Overall Statistics of the MS Subscale Score and Modified Fatigue Impact Scale (MFIS) Score
MOG Positive Patients vs Members Of Their Household Who Don’t Have MOGAD

When we compared the data of the MS Subscale Scores and the Modified Fatigue Impact Scale (MFIS) Scores for both MOG Positive Patients and Members Of Their Household Who Don’t Have MOGAD, it was apparent that MOG Positive Patients experienced higher MEAN, MEDIAN and MAX Subscale Scores in the Physical, Cognitive and Psychosocial department, attributing to a higher Total MFIS Score compared to Members Of Their Household Who Don’t Have MOGAD.

MOG Positive Patients had the highest MEAN Cognitive Subscale Score out of the three subscale categories, and a MEDIAN of 22 compared to the MEAN Score of Members Of Their Household Who Don’t Have MOGAD with a total of 16.8 and a MEDIAN Score of 17.

The Physical Subscale Scores were slightly higher In MOG Positive Patients, with a MEAN Score of 17.45 and a MEDIAN Score of 23 compared to the MEAN Score of Members Of Their Household Who Don’t Have MOGAD with a total of 16.7 and a MEDIAN Score of 16.5.

All in all, the overall Total MFIS Score is relatively higher in MOG Positive Patients compared to Members Of Their Household Who Don’t Have MOGAD, confirming that fatigue does exist and should warrant further investigation and research in MOG Antibody-Disease (MOGAD).

Please note that this data was represented based on the opinion and ratings of the respondents.

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