

# Ignition Survey Results: *MOG-AD Treatment Practices*



Siegel  
Rare Neuroimmune  
Association



# Survey Background and Objectives



The MOG Project partnered with the Siegel Rare Neuroimmune Association and The Sumaira Foundation to better understand treatment practices within the MOG-AD community



267 MOG-AD Patients and Caregivers completed the survey in April and May 2020



Respondents were recruited via social media and the Siegel Rare Neuroimmune Association database



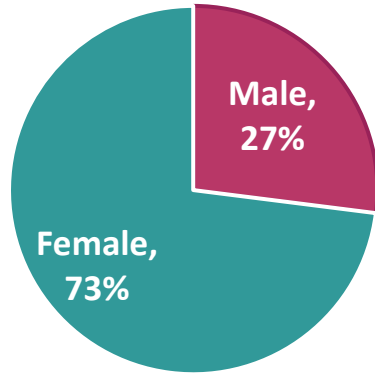
Survey questions focused on acute and preventive treatments and associated side effects

# 178 survey respondents were MOG-AD patients, 89 were caregivers responding on behalf of the MOG-AD patient

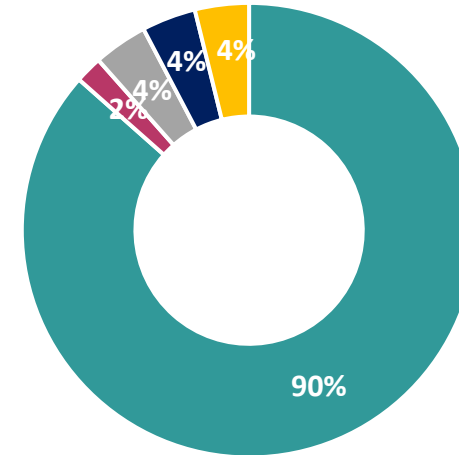


Respondent Demographics

### Gender (% of respondents)

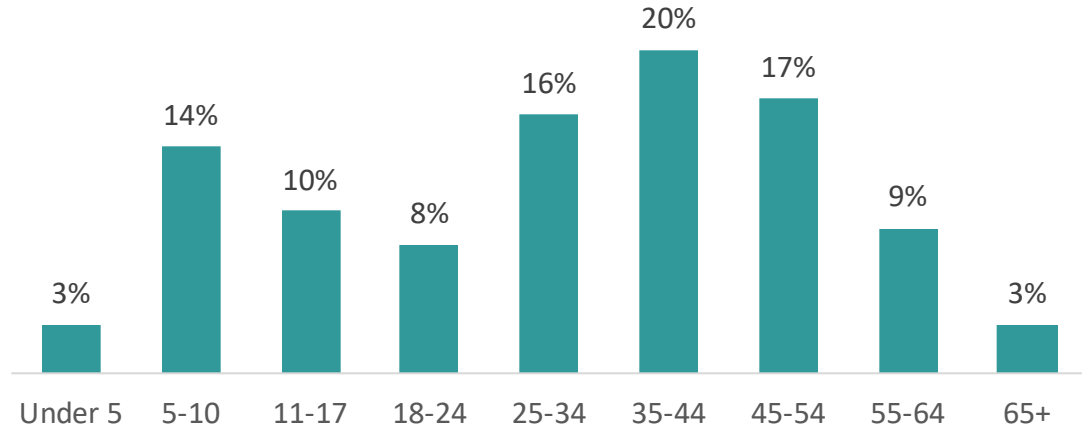


### Race/Ethnicity (% of respondents)



Note: Respondents could select more than one race/ethnicity

### Age (% of respondents)



- White/Caucasian
- Black/African American
- Hispanic/Latino
- Asian/Asian American
- Another Race

Most survey respondents were from the US (70%), followed by the UK (8%), Australia (8%) and Canada (5%); other areas represented include Africa, Asia, Europe, India and Russia

Note: All findings were self-reported by MOG-AD patients or their caregivers

# Most survey respondents are on preventive treatment and have been prescribed treatments during attacks/relapses



89% of patients were prescribed an **acute treatment** for their most recent attack/relapse

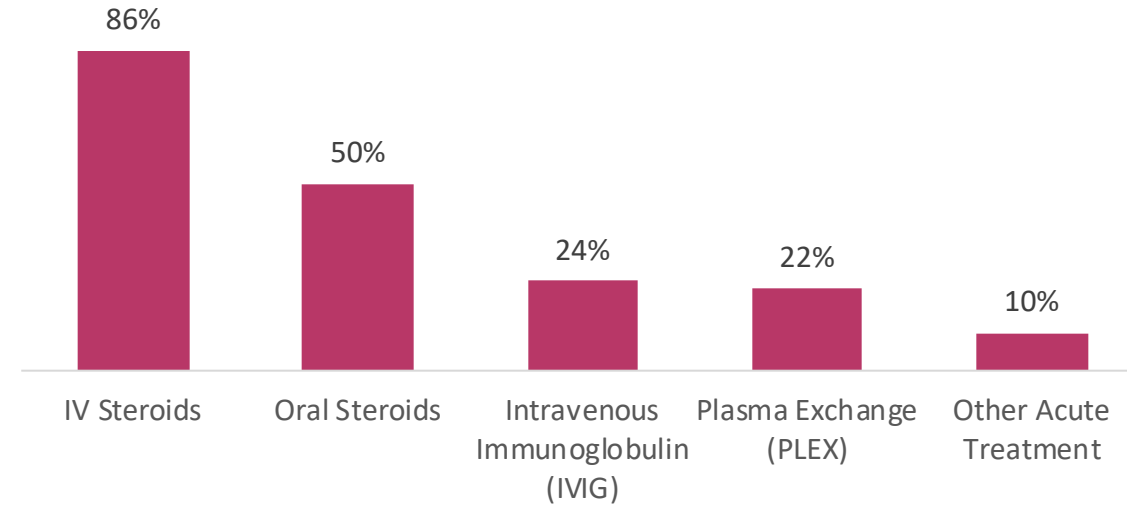


69% of patients are currently on **preventive treatment** for MOG-AD

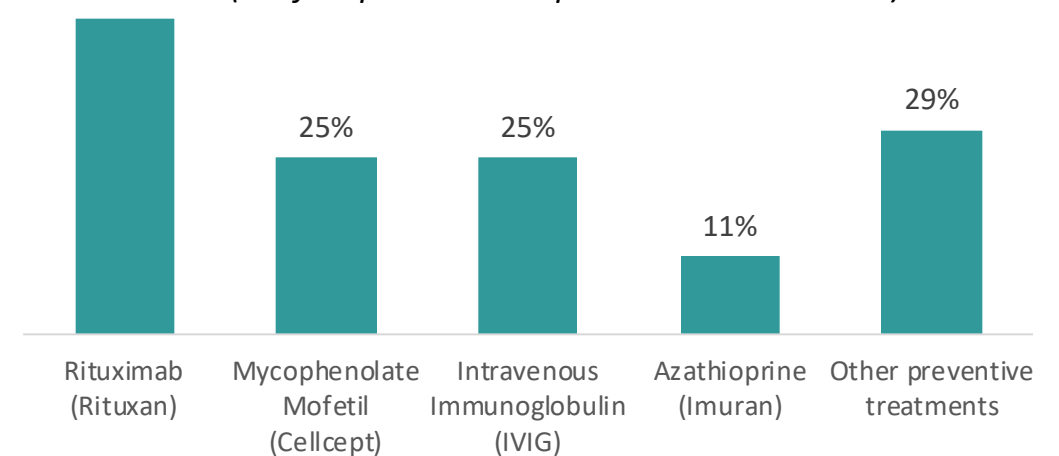


*“Other preventive treatments” include Oral Steroids, Ocrelizumab/Ocrevus, Vitamin D, Tocilizumab/Actemra, Methotrexate, Gabapentin*

**Acute Treatments Prescribed**  
(% of respondents who received acute treatments)



**Preventive Treatments Prescribed**  
(% of respondents on preventive treatments)



Note: All findings were self-reported by MOG-AD patients or their caregivers

# Many survey respondents have experienced side effects from treatment



*% of survey respondents reporting side effects:*

**66%** on acute treatments

**32%** on Mycophenolate Mofetil (Cellcept)

**42%** on Azathioprine (Imuran)

**49%** on Rituximab (Rituxan)

**53%** on Intravenous Immunoglobulin (IVIg)

*Note: All findings were self-reported by MOG-AD patients or their caregivers*

# 66% of patients who were prescribed acute treatments for their most recent attack or relapse report experiencing side effects



## Common Side Effects by Treatment

### IV/Oral Steroids

[86% (IV)/50% (Oral) respondents prescribed]

*“Increased heart rate and insomnia”*

*“Bad taste”*

*“Night sweats”*

*“Ravenous appetite, hyperactivity”*

*“Irritability”*

*“Weight gain”*

*“Prednisone-induced diabetes”*

*“Moon face”*

*“Elevated heart rate from IV steroids”*

*“Aggressive”*

*“Loss of bone density”*

*“Dizziness shakiness brain fog fatigue”*

### Plasma Exchange (PLEX)

[22% respondents prescribed]

*“After multiple rounds of plasmapheresis more fatigued than normal with a slow to no bounce back”*

*“Low fibrinogen and had to have a plasma transfusion”*

*“Blood clot in basilic vein”*

*“Fatigue post treatments”*

### IVIG

[24% respondents prescribed]

*“Major headache, throwing up, low grade fever, redness on her face”*

*“Fatigue, lethargy, nausea”*

*“Aseptic Meningitis”*

*“Silent Stroke”*

*“Severe headaches from the IVIG for a couple of days”*

*Note: All findings were self-reported by MOG-AD patients or their caregivers*

# 45% of patients on preventive treatment are currently on Rituximab (Rituxan)

49% of these patients reported experiencing side effects



**Hives, itching, and fatigue were most commonly mentioned side effects**

*“Had slight allergic reactions first couple of times (itching in ears and pharynx and mild sinus congestion). Last administration was fine.”*

*“Hives, cough, chills, itchy throat, feeling like throat closing up, wheezing.”*

*“Itchy throat, ears, cough, sneezing”*

*“Migraines”*

*“Severe colds for several days.”*

*“Fatigue and body aches”*

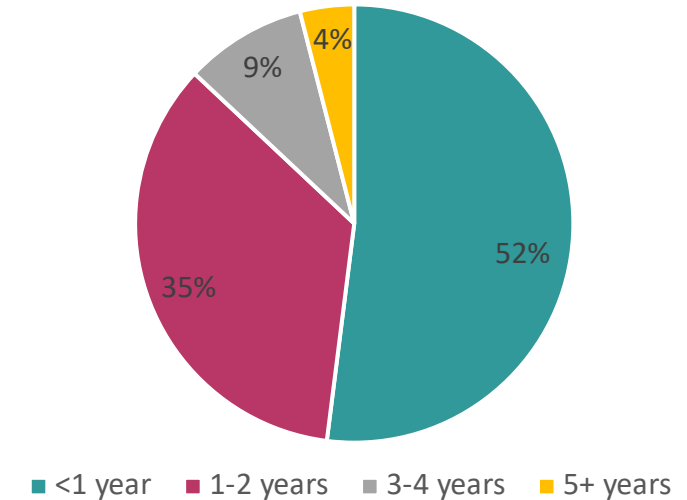
*“Skin rash”*

*“Extreme fatigue following initial dose and second dose”*

*Constant breakout of fever/cold sores on my lips for about 2 months.*

*Tickle in throat, persistent dry cough for a week after the infusion.*

**Time on Treatment**  
(% of respondents)



**More than half of survey respondents have been on Rituximab <1 year**

*Note: All findings were self-reported by MOG-AD patients or their caregivers*

# 25% of patients on preventive treatment are currently on Mycophenolate Mofetil (Cellcept)

32% of these patients reported experiencing side effects



***Nausea, upset stomach, and diarrhea were most commonly mentioned side effects***

*“Initial side effects were an upset stomach and diarrhea for the first month or so.”*

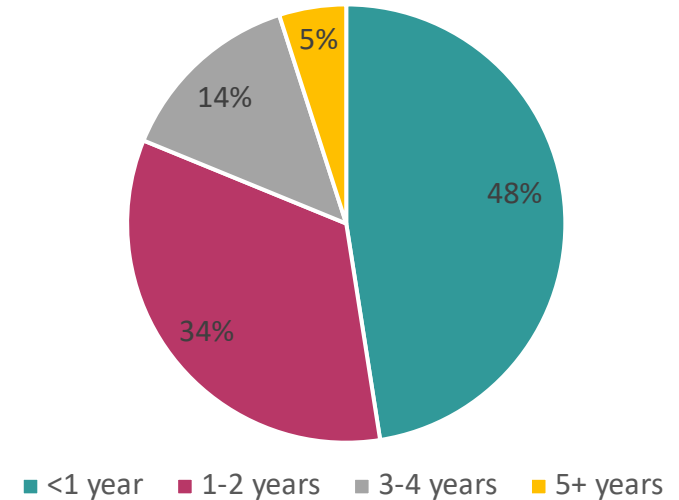
*“Nausea and continuous vomiting led to dehydration and a visit to A&E for drips.”*

*“Stomach cramps immediately after taking if I don't take it with food. These side effects went away after the first couple weeks.”*

*“Nausea and diarrhea and some stomach for the first couple of months.”*

*“Severe permanent Gastrointestinal issues.”*

**Time on Treatment**  
(% of respondents)



**About half of survey respondents have been on Mycophenolate Mofetil <1 year**

*Note: All findings were self-reported by MOG-AD patients or their caregivers*



# 25% of patients on preventive treatment are currently on Intravenous Immunoglobulin (IVIg)

53% of these patients reported experiencing side effects



**Headaches, many severe, and nausea/vomiting were most commonly mentioned side effects**

*“Mild, frontal headache, fatigue, mild nausea.”*

*“Headaches, migraines, exhaustion, nausea and vomiting for up to 3 days after the infusion.”*

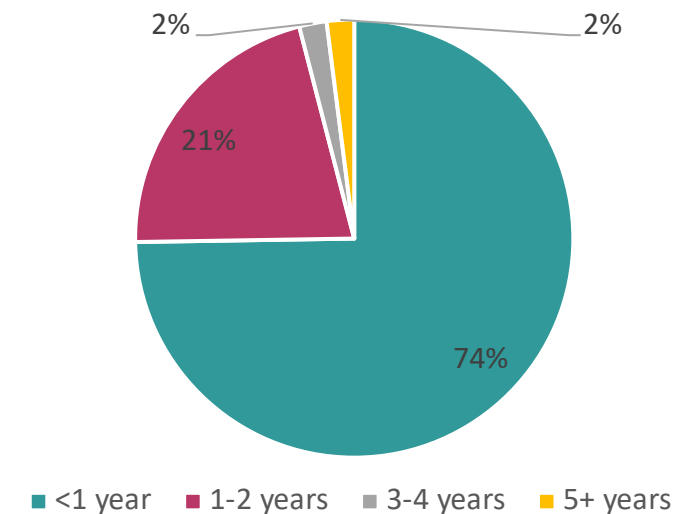
*“Severe headache, low grade fever, and vomited.”*

*“Severe headache, nurses add saline to my treatment and it helps tremendously. Slowing down the intake.”*

*“Migraines for 2 days post infusion.”*

*“Aseptic meningitis 3 times. Had to stop, went over to sub q igg and plex.”*

**Time on Treatment**  
(% of respondents)



**Nearly 3 in 4 survey respondents have been on IVIg for less than one year**

*Note: All findings were self-reported by MOG-AD patients or their caregivers*

# 11% of patients on preventive treatment are currently on Azathioprine (Imuran)

42% of these patients reported experiencing side effects



**Hair loss and nausea were most commonly mentioned side effects**

*“Hair loss. Dropped down to 50mg per day and it grew back. Still have slight hair loss.”*

*“Recurrent thrush and aches”*

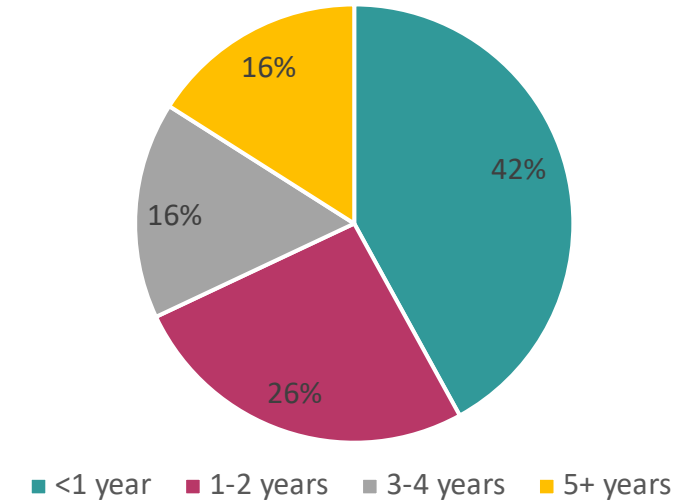
*“Fatigue, nausea, mild hair loss/thinning”*

*“Nausea, fatigue, hair thinning and lab tests indicate mild effects on my liver.”*

*“Nausea when taking in the morning. Switched to evening and no more side-effects.”*

*“Nausea and stomach discomfort immediately after taking medication. Possible link to higher blood pressure.”*

**Time on Treatment**  
(% of respondents)



**About 70% survey respondents have been on Azathioprine 2 years or less**

This survey was brought to you by:



In partnership with:



*Special thanks to the members of the MOG-AD community and their caregivers for participating in this survey.*