

# MOGAD Research Survey



## The patient experience up to diagnosis

Myelin Oligodendrocyte Glycoprotein Antibody Disease (**MOGAD**) is a rare condition that causes inflammation, or swelling, of the central nervous system – the optic nerve, brain, and/or spinal cord.<sup>1</sup>

**MOGAD** is thought to be caused by autoantibodies, which are parts of your immune system that mistakenly target healthy proteins in the body instead of harmful things like bacteria and viruses.<sup>1</sup>

In **MOGAD**, these autoantibodies damage the MOG protein located on the outer surface of the myelin sheath, a protective coating your nerve tissue in the central nervous system.<sup>1</sup>

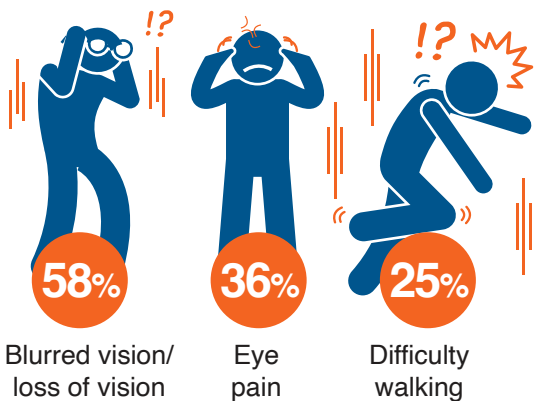
**MOGAD** is now recognised as a distinct disease separate from multiple sclerosis (MS) and neuromyelitis optica spectrum disorder (NMOSD).<sup>2</sup>

Early diagnosis of **MOGAD** is critical, but diagnosis can be slowed down by lack of awareness of the condition and varying access to MOG antibody tests between countries.

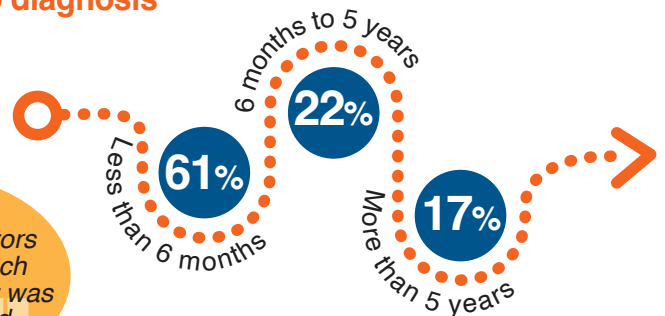
To better understand the experiences and challenges faced by people diagnosed with **MOGAD**, we asked 204 patients and caregivers from 21 countries for their views in an a research survey.<sup>3</sup>

### ★ Key findings from the survey: diagnosis experience<sup>3</sup>

#### First **MOGAD** symptoms prompting patients to seek medical care

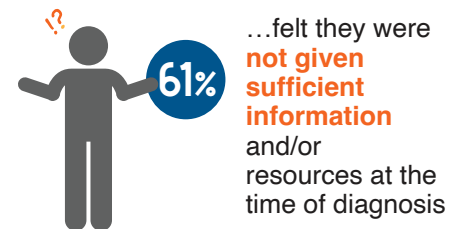


#### Length of time from first **MOGAD** symptoms to diagnosis

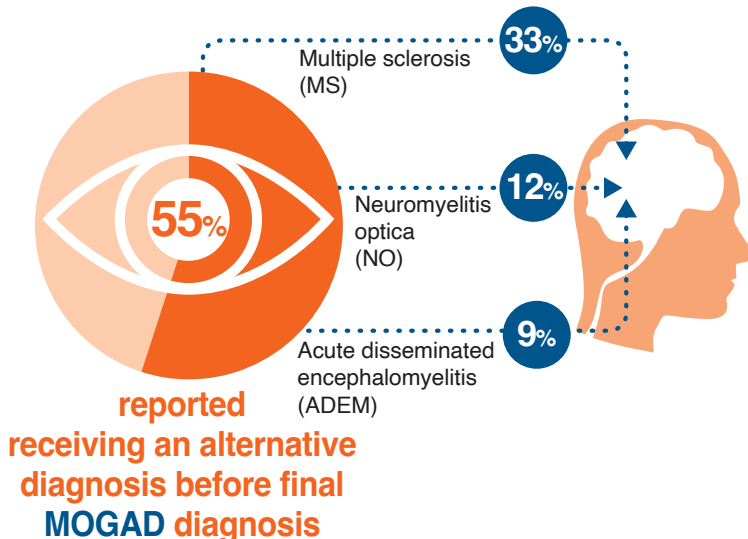
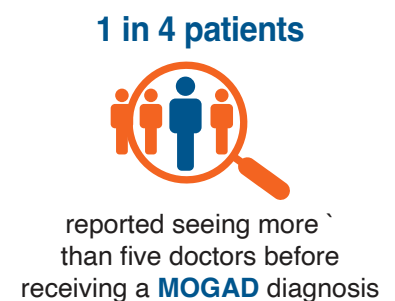
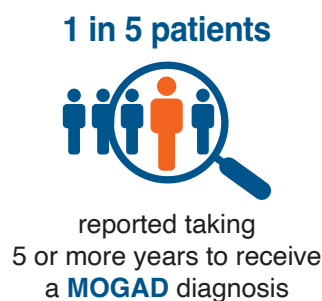


*When I was diagnosed, doctors didn't know much about MOGAD. It was very scary and frustrating*

#### Information received from healthcare professionals



#### Delays from seeking support to a confirmed **MOGAD** diagnosis





## ★ Key findings from the survey: impact on delay of MOGAD diagnosis<sup>3</sup>



...reported that their overall health and well-being were negatively affected by the disease

A delayed/alternative diagnosis of MOGAD was associated with:



Increased frustration



Physical impairment



Reduced health-related quality of life

*My daughter...has permanent damage to her optic nerves and we often wonder if she could have avoided the permanent damage had she been diagnosed and treated more quickly point to delay in MOGAD diagnosis*

### Delay in MOGAD diagnosis

There was a perception that the delay in MOGAD diagnosis caused long-term adverse health consequences in:



Vision impairment



Neurological disorders not including mental health



Bladder issues

Respondents reported that delayed diagnosis led to other health problems, such as adverse impacts on the ability to perform daily living and social activities and on attendance and performance at work or school.

### Receiving a final MOGAD diagnosis

61%

...reported reduced feelings of distress, depression, anxiety, or fear

*Doctors didn't know what I had...lack of knowledge. Some tests were not available at that time*

## ★ People with MOGAD face several challenges in securing a diagnosis:

Most people (including many doctors) have never heard of MOGAD and don't realise all their symptoms may be connected to a single distinct condition

MOGAD is often misdiagnosed as other conditions, meaning a lot of patients have to see multiple specialists over several years before getting an accurate diagnosis

Access to diagnostic tests is limited in some countries, so even doctors who recognise MOGAD may not be able to confirm the diagnosis

These challenges, and the delay they cause, have a significant impact on people with MOGAD and their loved ones.

To improve outcomes for people with MOGAD, more should be done to raise awareness about MOGAD in the general public and among the medical community. We must also make access to diagnostic tests more consistent between countries so that MOGAD can be confirmed, and treatment can begin.

1. Mayo Clinic. Myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD).

Available from: <https://www.mayoclinic.org/diseases-conditions/mogad/symptoms-causes/syc-20560476>. Accessed June 2024

2. Hegen H, Reindl M. Recent developments in MOG-IgG associated neurological disorders. *Ther Adv Neurol Disord.* 2020;13:1–20.

3. Santoro JD, Gould J, Panahloo Z, et al. Patient Pathway to Diagnosis of Myelin Oligodendrocyte Glycoprotein Antibody-Associated Disease (MOGAD): Findings from a Multinational Survey of 204 Patients. *Neurol Ther.* 2023;12(4):1081-101.

