My Vision Faded to Darkness.

"My journey began with a mild blur in my vision. After months of misdiagnosis, I was told I had MS. A year later, tests revealed I had NMOSD. The delayed diagnosis meant I didn't get the right treatment. I lost much of my vision and can no longer walk unaided. My life could have been different with an early diagnosis."

Pascale, a former musician living with NMOSD

When Your Body Attacks Itself

Understanding NMOSD & MOGAD

Neuromyelitis optica spectrum disorder (NMOSD) and Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD) are rare, disabling diseases where the immune system mistakenly attacks cells in the central nervous system. Their symptoms overlap with MS, but they have different underlying disease processes and require different treatments.

NMOSD

Primarily affects the spinal cord and optic nerves

Typical onset between ages 32–45

Affects 0.7–10 people per 100,000

More common in Black and East Asian populations

5–9 times more common in women than men

MOGAD

Typical onset around age 30

Affects 1.3–2.5 people per 100,000 globally

Symptoms include paralysis, pain, visual impairment, fatigue, and spasticity

Why Time Matters

Symptoms of NMOSD and MOGAD often mimic MS, leading to misdiagnosis—making early and accurate diagnosis crucial.

This requires prompt referral to specialist neurology services equipped with advanced diagnostic tools such as MRI scanners using standardised protocols.

Without this comprehensive approach, patients risk inappropriate treatments and unnecessary disability progression that could have been prevented through timely intervention.

Breaking Barriers

Key recommendations :

- Improve diagnosis speed and specialist referrals
- Implement person-centered care with shared decision-making
- Develop specialised centers with better diagnostic tools
- Standardise data collection and support research collaboration
- Ensure affordable treatments and comprehensive patient support

Source:
Butzkueven H, Giovannoni G, Arkelsten S, et al. Brain Health – Time Matters: Report on MS, NMOSD, and MOGAD Care. MS Brain Health; 2024. https://www.msbrainhealth.org/. Accessed February 26, 2025.