Neuromyelitis Optica Spectrum Disorder (NMOSD)

Neuromyelitis Optica Spectrum Disorder (NMOSD) is a rare, devastating autoimmune disease of the central nervous system, characterized by relapses where each individual attack can result in cumulative disability, including blindness and paralysis, and sometimes premature death.[1-3]

Signs and Symptoms Can Include:[4]

- Double vision
- Pain upon eye movement
- Loss of vision in one eye
- Sudden vision loss
- Intense nerve pain
- Feeling of banding or tightening around the waist
- Abnormal skin sensations (e.g., tingling, prickling or sensitivity to heat/cold)
- Loss of sensation in arms and/or legs
- Lack of coordination
- Paralysis of limbs
- Loss of bladder/bowel function

NMOSD primarily affects **women** and people of **African heritage**, including African Americans.[5-7]

The median age of onset is **39 years old**.[7]

In a study of 21 patients with NMOSD, most patients reported at least some problems with **mobility, pain/discomfort and/or anxiety or depression**.[8]

Attacks, referred to as relapses, can cause **irreversible damage** primarily to the optic nerve and spinal cord, which could lead to long-term disability.[3,5,7,9]

What Causes NMOSD?

In NMOSD, the immune system malfunctions and attacks the central nervous system (CNS). These attacks lead to inflammation in the tissues of the CNS damaging the optic nerve and/or spinal cord, which can cause blindness, paralysis and sometimes premature death.[1-3,10]

Complement activation is one of the underlying causes of damage in NMOSD.[10] The complement system is a vital component of the immune system and helps to protect against infection.[11]

In NMOSD, complement activation triggered by auto-antibodies against a specific protein (aquaporin-4 [AQP4]) present on certain cells in the CNS leads to inflammatory damage and neuronal destruction.[10,12,13]

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How Is NMOSD Diagnosed?

The journey to diagnosis can be long. Patients often visit numerous specialists (some of who may be unfamiliar with NMOSD) and undergo many rounds of testing, which can result in misdiagnosis.

NMOSD is often misdiagnosed as multiple sclerosis (MS), even though they are two distinct diseases.[3,7]

A neurologist or neuro-ophthalmologist diagnoses NMOSD by one or more of the following:[1,4]

- A blood test for the NMOSD-specific autoantibody (AQP4-Immunoglobulin G)
- At least one to two core clinical symptoms (e.g. optic neuritis or acute myelitis)
- MRI of brain, spinal cord or optic nerve
- Process of elimination after careful study of location and length of lesions for select patients

How Is NMOSD Managed?

Relapses are unpredictable, and each relapse can result in permanent cumulative disability.[1-3]

In a study of 106 patients with anti-AQP4 antibody-positive NMOSD:[1]

Within ~6 years of disease onset:

- 34% sustained permanent motor disability
- 23% became wheelchair dependent
- 18% suffered permanent visual disability

Within ~8 years of disease onset:

- 9% died

"My hope for the future for the NMOSD community is for all of us to live the best possible lives that we can live and without fear of a relapse and just live as happily as we can and not feeling so debilitated. I want the world to know about NMOSD."

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LIVING WITH NMOSD

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