Your mother's strength.
Your auntie's confidence.
Your grandparents' determination.
A history of perseverance.

Neuromyelitis optica spectrum disorder (NMOSD) is a rare disease that disproportionately impacts women of African and Asian ancestries. But while NMOSD may be linked to your ancestry, so are the values that fuel your advocacy for a proper diagnosis.

Read on to learn more about NMOSD and how ProjectRED™ can help you access the care you need.

PROJECT RED™
RACIAL & ETHNIC DISPARITIES IN NMOSD

WHAT IS NMOSD?

Neuromyelitis optica spectrum disorder (NMOSD) is a rare, chronic autoimmune disease. It affects the central nervous system, which includes the brain, spinal cord, and optic nerves (eyes). Most people who have NMOSD test positive for a particular autoantibody called the anti-aquaporin-4 antibody.

Visit NMOSD.com to learn more.

NMOSD is rare.

~15,000 people

are living with NMOSD in the United States.

NMOSD tends to first impact people before they turn 40.

39 years of age

is the median of onset of NMOSD, though signs can start at any age.

Women are more likely to be diagnosed with NMOSD than men.

5 to 1 ratio

of women to men who are diagnosed with NMOSD.

Understanding NMOSD attacks

When you have NMOSD, your body damages its own healthy cells. NMOSD attacks are defined as the start of new or worsening symptoms that last longer than 24 hours when you've been stable for at least 30 days (without an alternative reason, such as infection or fever). They usually affect the spinal cord or the optic nerve and can potentially lead to mobility issues and/or permanent vision loss.

SYMPTOMS CAN INCLUDE:

BLURRY VISION OR BLINDNESS

WEAKNESS OR PARALYSIS IN THE LEGS OR ARMS

PAINFUL SPASMS

NUMBNESS

SEVERE NAUSEA AND VOMITING

PERSISTENT HICCUPS

BLADDER OR BOWEL DYSFUNCTION

SLEEPING PROBLEMS

Not all attacks look the same for every person, but each one may cause permanent damage. **Make sure you let your doctor know if you think you've had an attack.**

Your symptoms could be the key to the right diagnosis.

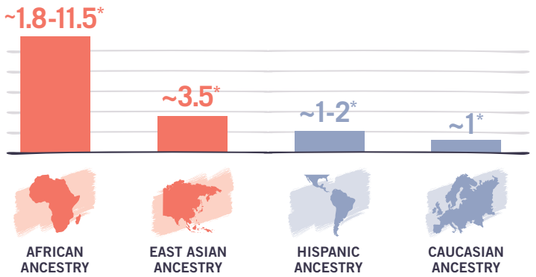
Talk to your doctor if you have experienced any of these symptoms and have not been diagnosed with NMOSD. The right diagnosis is the first step to reducing your risk for future attacks.

YOUR ANCESTRY MATTERS

Your ancestry may play a role in your likelihood of having NMOSD

People of African and Asian ancestries are diagnosed with NMOSD more often than people of Caucasian ancestry.

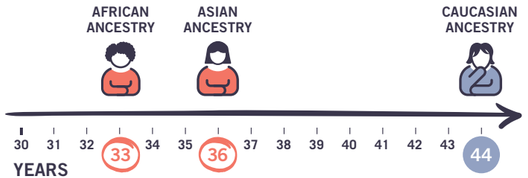
ANCESTRIES MOST IMPACTED BY NMOSD



*Estimated cases per 100,000.

People of African and Asian ancestries start to experience their first NMOSD symptoms at an earlier age than people of Caucasian ancestry.

AGE OF NMOSD SYMPTOM ONSET



Your ancestry may also affect the severity of your first attack

PERCENTAGE WITH SEVERE FIRST ATTACK

DISEASE WORSENING

This group may be at an increased risk for disease worsening from these attacks.

Every attack can further damage your central nervous system, which can impact your vision and mobility.

IF YOU ARE AT HIGHER RISK FOR NMOSD, DON'T WAIT UNTIL YOUR NEXT ATTACK TO TALK TO YOUR DOCTOR.

STAND UP FOR YOUR HEALTH

You deserve an *accurate diagnosis*

ASK YOUR DOCTOR IF NMOSD HAS BEEN CONSIDERED

You might still be searching for a diagnosis. Or maybe you were diagnosed with multiple sclerosis but are experiencing new symptoms that overlap with NMOSD. You could even be diagnosed with NMOSD but still are experiencing attacks. Either way, an open and honest conversation with your doctor is the first step in creating the best plan to manage your disease and reduce your risk of attacks.

ASK YOUR DOCTOR FOR A CELL-BASED ASSAY BLOOD TEST

When you have NMOSD, misdiagnosis is possible because this disease has overlapping symptoms with other conditions. A cell-based assay, or CBA, is used to detect whether anti-aquaporin-4 antibodies are present in your blood. Most people who are diagnosed with NMOSD have these antibodies. Don't hesitate to ask for the CBA test—even if your doctor does not bring it up.

While another test called the ELISA is also available, it may not be as accurate in detecting anti-aquaporin-4 antibodies. **A cell-based assay blood test could be one of the most important steps for getting the right diagnosis.**

ELISA, enzyme-linked immunosorbent assay.

When life gets in the way...

You're busy and you have responsibilities.

Talk to your doctor about anything that might interfere with your care and treatment, such as:

- **No access to reliable transportation**
- **Financial challenges**
- **Childcare needs**
- **Language barriers**

They may be able to help you access support and resources so you can receive the best care possible.

ProjectRED™ HAS IDENTIFIED HELPFUL RESOURCES FOR PEOPLE OF AFRICAN OR ASIAN ANCESTRY

In addition to community advocacy and support organizations, there are several resources that you might find helpful.

The Guthy Jackson® Charitable Foundation provides multilingual NMOSD resources for patients who are non-native English speakers.
guthyjacksonfoundation.org/nmoresources

The Sumaira Foundation helps raise awareness of NMOSD and supports patients with content in multiple languages.
sumairafoundation.org/nmosd-resources

The Siegel Rare Neuroimmune Association (SRNA) supports those living with NMOSD through advocacy, education, clinical research, and more.
wearesrna.org

NMOSD.com is a one-stop shop for learning more about this condition, from how it's diagnosed to how to manage it and much more.

PROJECT RED™
RACIAL & ETHNIC DISPARITIES IN NMOSD

ProjectRED™ is on your side

ProjectRED™ recognizes the role your ancestry plays in your life—and your risk of having NMOSD. The goals of this initiative include helping you:

- Access the care you need, when you need it
- Build an open and trusting relationship between you and your doctor
- Receive a timely diagnosis and begin treatment as soon as possible
- Work with your healthcare team to understand and address your unique risks for NMOSD

Visit AlexionProjectRED.com to learn more.