THE Sumaira FOUNDATION

UNDERSTANDING

NMOSD AND MOGAD

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THE Sumaira FOUNDATION

Awareness • Community • Research • Advocacy

The Sumaira Foundation (TSF) is a global nonprofit organization dedicated to raising awareness of NMOSD, MOGAD and other rare neuroimmune conditions, building communities of support for patients and their caregivers, supporting research and advocating on behalf of patients.

At TSF, we are proud to be patient-led, patient-powered, science-driven and therapy-agnostic.

Visit our website to meet our team including the Board of Directors, Medical Advisory Board and TSF Ambassadors
www.sumairafoundation.org

Illustrated by Maya Alballa

TSF's mascot is a unicorn,
in honor of a pediatric NMOSD patient who passed away in 2019.

MEET SUMAIRA

In August 2014, Sumaira was diagnosed with seronegative neuromyelitis optica (NMO) following a sudden onset of severe vision loss and weakness/numbness. Less than two months later, while still in the hospital, she established The Sumaira Foundation (TSF).

After earning her bachelor's degree from Boston University, Sumaira began her career in the healthcare sector, focusing on marketing, strategic planning and business development. She spent years working at Brigham and Women's Hospital and Mass General Brigham, where she cultivated global partnerships to enhance business performance, elevate care delivery and advance medical education both in the US and abroad.

Her own diagnosis revealed critical gaps in patient education, community engagement and advocacy. This inspired her to take initiative, equipping patients and caregivers with the knowledge, tools and support to become empowered advocates for their health. Her work is fueled by a deep and unwavering commitment to health equity.

Sumaira is a classically-trained Kathak dancer and was crowned the first Miss Bangladesh-USA in 2015. She is fluent in Bengali and Hindi.

Sumaira currently serves as the Executive Director of The Sumaira Foundation.

WHAT IS NMOSD?

Dr. Eugène Devic

In 1894, French neurologist, Dr. Eugène Devic and his student, Fernand Gault, described a rare nervous condition that affected the spinal cord and optic nerves that resembled multiple sclerosis.

Today this disorder is referred to as Devic's disease or neuromyelitis optica spectrum disorder (NMOSD).[1]

COMMON SYMPTOMS:

- **Bladder/bowel dysfunction**
- **Blurred and/or double vision**
- **Brain fog**
- **Chronic fatigue**
- **Color vision deficiency**
- **Coughing**
- **Dizziness**
- **Heat intolerance**
- **Hiccups**

Neuromyelitis optica spectrum disorder (NMOSD) is a rare neuroimmune condition in which the immune system attacks cells in the central nervous system (CNS), mistaking them for foreign invaders.[2]

Rare disease patients benefit greatly from having a **multi-specialty care team.** In the case of NMOSD, these specialties may include rehabilitation medicine, urology, occupational therapy, ophthalmology, family planning, endocrinology, psychology and gastroenterology.

COMMON SYMPTOMS:

- **Numbness & tingling**
- **Paralysis**
- **Poor balance**
- **Slurred speech**
- **Spasticity**
- **Vision loss**
- **Vomiting**
- **Weakness**

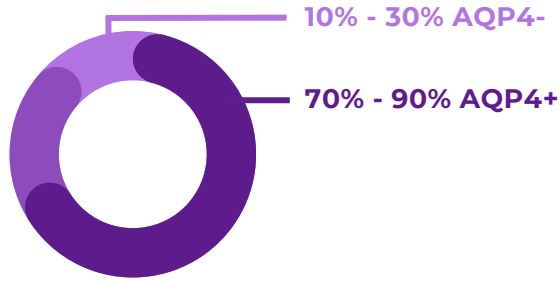
NMOSD Antibody

- **Aquaporin-4 positive (AQP4+)**
  More than half of the patients with NMOSD are AQP4 positive. But this means some patients do not show any AQP4 antibodies in the blood tests: these patients are **aquaporin-4 negative (AQP4-)**. Some **AQP4-** patients may even present with MOG antibodies.

- **Seronegative** can mean either lacking in AQP4 antibodies, MOG antibodies, or both types. This is called double seronegativity.[3]

NMOSD Patients

AQP4- vs APQ4+ diagnosis (%)



While study results vary, around 70-90% of NMOSD patients are **AQP4+**, meaning approximately 10-30% of patients are **AQP4-**.[4,5]

Disclaimer:

While this brochure provides useful information and resources for NMOSD, it is not a substitute for medical care and you should consult your healthcare provider for any health concerns.

TREATING NMOSD

NMOSD patients are advised to receive **long-term**, preventative therapies. The following FDA-approved therapies for **AQP4+** adults suppress the body's immune system to prevent a future relapse or attack throughout a patient's life. However, safety or effectiveness in children is not yet known.

SOLIRIS® (eculizumab) Injection for Intravenous Use 300 mg/30 mL vial

Soliris®
(infusion)[6]

uplizna® inebilizumab-cdon

Uplizna®
(infusion)[7]

ENSPRYNG® satralizumab-mwge subcutaneous injection 120 mg/mL

Enspryng®
(subcutaneous injection)[8]

ULTOMIRIS® (ravulizumab-cwvz) injection for intravenous use 300 mg/3 mL vial

ULTOMIRIS®
(infusion)[9]

Visit TSF's **NMOSD Therapies Chart** to learn more about your treatment options:

sumairafoundation.org/awareness/therapies-chart

In conjunction with the therapies listed, some patients may also receive **intravenous immunoglobulin (IVIg)**, an infusion treatment that manages immunodeficiency disorders. Immunoglobulin is a collection of immune system antibodies from donors.[10]

Acute attacks are suspected to last 24 hours or more. Acute treatments are **short-term**, intensive care to immediately control an attack. These include:

- **Steroids**
  (also known as methylprednisolone or IVSM which stands for intravenous solu-medrol) is administered via an infusion to decrease inflammation.[11]

- **Plasma exchange**
  (also known as PLEX or plasmapheresis) removes the antibodies by removing the body's unhealthy plasma from the blood intravenously, and is exchanged with healthy plasma.[12]

If you are in need of assistance to manage your care, visit this link:

sumairafoundation.org/financial-support

WHAT IS MOGAD?

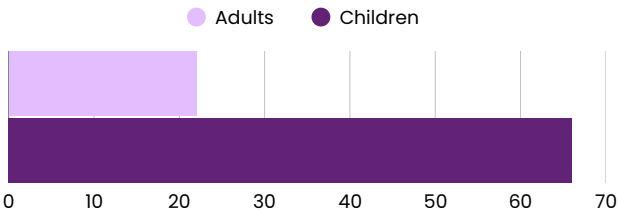
Myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) is a rare neuroimmune condition where MOG antibodies incorrectly target the MOG protein, which is located on the surface of myelin sheaths in the central nervous system.

Myelin sheaths are a fatty layer that wraps around nerve cells, protecting them and allowing electrical impulses to travel quickly.

Patients are diagnosed when MOG antibodies are present with a blood test, which is confirmed by observing damaged myelin sheaths around the nerve cells.[13]

MOGAD is 3x more common in children

MOGAD incidence (%)



The incidence of **MOGAD in children** was estimated in a study to be approximately three times that of adults.[18,19]

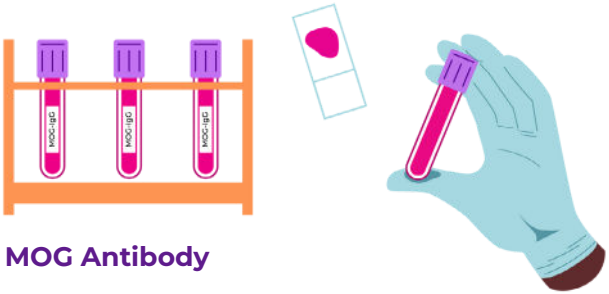
Disclaimer:

While this brochure provides useful information and resources for MOGAD, it is not a substitute for medical care and you should consult your healthcare provider for any health concerns.

Rare disease patients benefit greatly from having a **multi-specialty care team.** In the case of MOGAD, these specialties may include rehabilitation medicine, urology, occupational therapy, ophthalmology, family planning, endocrinology, psychology and gastroenterology.

COMMON SYMPTOMS:

- **Bladder/bowel dysfunction**
- **Color vision deficiency**
- **Eye pain**
- **Headaches**
- **Hiccups**
- **Numbness & tingling**
- **Paralysis**
- **Paraparesis**
- **Spasticity**
- **Weakness**
- **Vision loss**
- **Vomiting**



MOG Antibody

The MOG antibody (**MOG-IgG**) is a biomarker in the blood, since it can help diagnose someone with MOGAD if found present.[2]

According to the 2023 International MOGAD Panel Proposed Criteria, patients need to test positive for the MOG antibodies to have an official diagnosis.[14]

An **antibody titer** is a laboratory test that measures the amount of antibodies in a blood sample. MOG antibody titer levels are usually higher during a relapse than while in remission; however, patients may experience relapses with stable titer levels, or titer level decreases. Although, following negative results, some patients can return to having blood test results with a positive titer level. So be mindful that titers can fluctuate! [15,16]

TAKE NOTE:

While there is always an initial positive MOG antibody test for both monophasic and relapsing MOGAD, relapsing MOGAD may fluctuate in positivity overtime (meanwhile monophasic patient's antibody tests become negative).[15,16]

TREATING MOGAD

While a treatment is yet to be FDA-approved for MOGAD, other treatments can help.

Acute attacks are suspected to last 24 hours or more. Acute treatments are **short-term**, intensive care to immediately control an attack. These include:

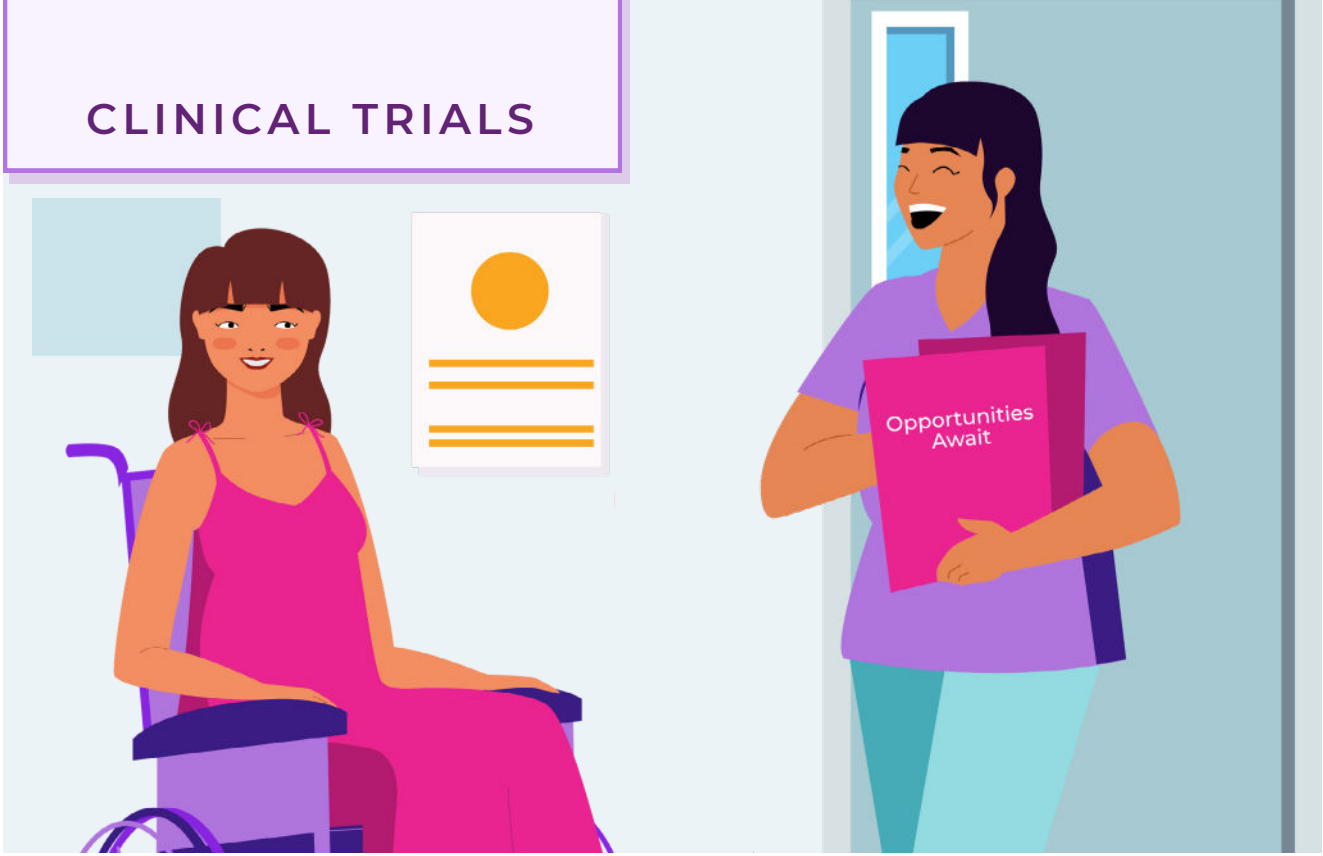
- **Steroids**
  (also known as methylprednisolone or IVSM which stands for intravenous solu-medrol) is administered via an infusion to decrease inflammation.[15,20]

- **Plasma exchange**
  (also known as PLEX or plasmapheresis) removes the MOG antibodies by removing the body's unhealthy plasma from the blood intravenously, and is exchanged with healthy plasma.[15,21]

Long-term preventative therapies such as **immunoglobulin (IVIg)** are given through the vein to suppress the body's immune system. This is often suggested to patients in order to prevent a future relapse or attack throughout their life.[15]

Turn the page to discover ongoing clinical trials and how you can take part in advancing research for MOG antibody disease.

CLINICAL TRIALS



cosMOG

cosMOG - UCB

The cosMOG study aims to understand how well-tolerated and effective an investigational drug called rozanolixizumab is in people with MOGAD. The investigational drug will be given weekly as an infusion under the skin.[22]

METEOROID

Meteoroid - Genentech

This clinical trial is comparing satralizumab with placebo, with or without background therapy, in people with MOGAD. Satralizumab is self-administered subcutaneously every four weeks.[23]

ADVOCACY & COMMUNITY

No one should ever have to navigate their disease journey alone. Explore some of the ways in which you can connect with the NMOSD & MOGAD communities through our website: **www.sumairafoundation.org**

Patient Days

TSF hosts patient events to foster community, education and connection. Find or request a TSF event near you!

Support Group Meetings

Join a virtual peer-to-peer support group meeting led by TSF Ambassadors.

TSF Ambassadors

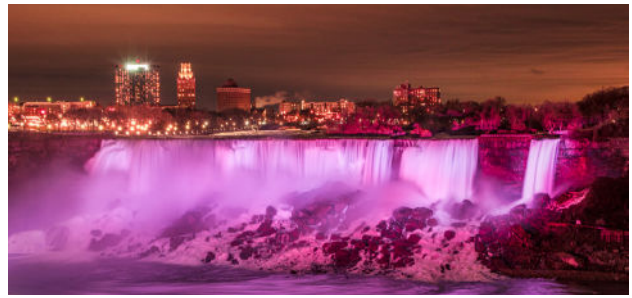
TSF Ambassadors are patients, caregivers and clinicians leading the TSF mission from 30+ countries. Connect with a TSF Ambassador near you.

NMO Awareness Month (March)

March is celebrated as NMO Awareness Month. Join the global movement to raise awareness and empower the community. TSF Ambassadors secure state proclamations and landmark illuminations in honor of our NMO Awareness Month.

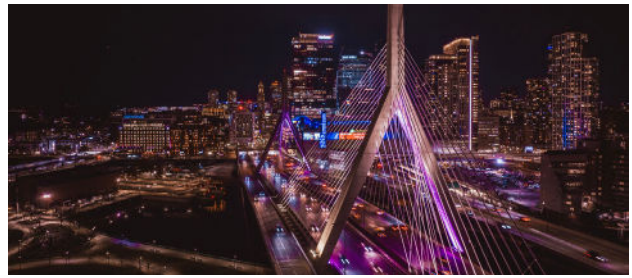
MOG Awareness Month (April)

April is celebrated as MOG Awareness Month. Join the global movement to raise awareness and empower the community. TSF Ambassadors secure state proclamations and landmark illuminations in honor of our MOG Awareness Month.



Niagara Falls

Niagara Falls, NY

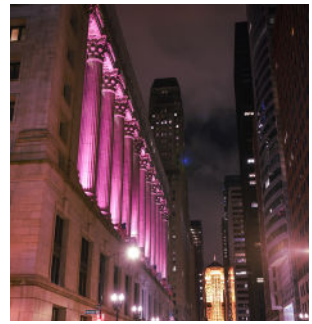


Zakim Bunker Hill Memorial Bridge

Boston, MA

Empire State Building

New York, NY



The City Hall-County Building

Chicago, IL

PATIENT EDUCATION

Knowledge is power and can lead to better health outcomes. Visit TSF's global website to **'get smart'** on your disease from the patient education resources outlined below and more!

Demystifying NMO & MOG Podcast

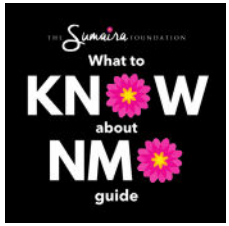
TSF Research Summaries

From the Experts Webinars

Understanding MOGAD Webinars

MOGmentum Infographics

Voices of NMO & MOGAD Stories



What to KNOW about NMO Guide

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