



Neuromyelitis Optica

NMO

What You Need to Know

A guide for patients, their families and caregivers

SECOND EDITION

EDUCATION • RESOURCES • RESEARCH • AWARENESS

Providing information and support for those living with NMO



You may have NMO –
but NMO does not have you.





Welcome. You are not alone...

N•M•O. Three letters that have changed our lives forever. When Ali was diagnosed with NMO seven years ago, there was precious little information to be found and like so many we felt alone. We soon learned how little work was being done to solve this disease and The Guthy-Jackson Charitable Foundation was formed. Since that time remarkable progress has been made, **leading the way** as we move forward to more work ahead.

Having just read this Second Edition of our Foundation's NMO Patient Guide, I realize that as an NMO community, we're not alone anymore. 10,000 readers eagerly reached for our First Edition NMO Guides with many later sending thoughtful notes of "Thanks." There has been a tremendous groundswell in our NMO advocacy community by those who live with NMO. Together we work to raise awareness of this rare disease, not just for our NMO community but for all who suffer from rare diseases, numbering 25 million in the U.S.

This Resource Guide for NMO is intended to offer help and guidance to all those who have been impacted by this rare disease.

With love and hope,
Victoria Jackson, Founder



How to Use This Book

This guide may be a companion, a mentor, a compass, a friend – all meant to support you on your journey with neuromyelitis optica (NMO) and/or neuromyelitis optica spectrum disease (NMOSD). While certain sections address NMO and NMOSD specifically, for simplicity in this guide, the abbreviation NMO will be used to mean both NMO and NMOSD. Whether you are a patient, a caregiver, a family member or someone who just wants to learn more about NMO, we hope that you can find some answers to unanswered questions, a helping hand where there was no help, or perhaps a sympathetic ear as you gain comfort and knowledge from the resources in this guide and in the foundation's online community. Because this book offers a great deal of information, we encourage you to pace yourself. In navigating the world of NMO, we hope this guide may serve as an interactive tool in which you can take notes, highlight text, keep a diary, write down more questions or ideas, and anything else you think will help you live with NMO. ***You may have NMO – but NMO does not have you.***

In an effort to address primary concerns of NMO patients, their families and caregivers, information is



presented in a simple, straightforward format. The content lists at the beginning of each section aim to assist in finding specific information.

This book provides information to NMO patients, caregivers, family and friends while addressing the unique challenges of living with an uncommon disease. Ask your doctor for advice regarding questions that arise as you read this book. In the back of this book is a “notes section” which is provided to record ideas, observations, or questions for visits to your doctor.

A valuable companion to this book is The Guthy-Jackson Charitable Foundation website:

www.guthyjacksonfoundation.org

There you will find ways to get involved to help cure NMO by visiting our NMO patient site, **NMOtion**, educate yourself about NMO research by reading scientific publications on Spectrum, and links to social media like our Facebook and Twitter communities. Many patients gain from these tools by connecting with others who are living with NMO.

Helpful website resources include: ■ information about NMO clinical trials, ■ video library called “NMO TV” containing videos that look at NMO from multiple perspectives, ■ published studies that speak to the evolving depth of research in NMO, ■ ways to join our advocacy community and raise awareness about NMO, ■ “Connect the Docs” and “Mapping NMO” to

assist in locating NMO clinicians and our community of NMO Advocates, ■ information on how to donate blood samples to our biorepository for NMO research, and ■ a link to our donation page for those who are able to donate to our cause. Any donation amount is welcome to help fund our mission to cure NMO. **The Guthy-Jackson Charitable Foundation allocates 100 percent of all donations directly to NMO research.**





The Guthy-Jackson Charitable Foundation is proud to facilitate awareness and education about NMO. It is important to note that information provided in “**NMO: What You Need to Know**” should not be used or considered as clinical advice, therapeutic recommendations, or medical treatment. For specific information and medical advice, consult your physician. The Guthy-Jackson Charitable Foundation does not endorse or recommend products, services, manufacturers, or assume any liability whatsoever for the use or content of this or any product or service mentioned.



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Preface

A diagnosis of neuromyelitis optica (NMO) and / or neuromyelitis optica spectrum disease (NMOSD) can be a confusing and frightening experience for NMO patients and loved ones. Many newly diagnosed patients may feel overwhelmed, powerless or alone. The resources contained in this book aim to provide information that may be helpful to empower those affected by NMO — and help NMO patients and their families understand that they are not alone — others travel this road with them. While certain sections



address NMO and NMOSD specifically, for simplicity in this guide, the abbreviation NMO will be used to mean both NMO and NMOSD.

How many people have NMO? This remains a difficult question to answer. However there is an emerging sense that the number of NMO cases has been underrepresented. This situation may be due to a previous lack of awareness of this disease, its underdiagnosis, and similarities that NMO shares with other autoimmune and neurologic conditions. Current studies indicate that the **incidence** (number of new cases) and **prevalence** (total number of active cases) of **NMO is likely greater than originally noted, as NMO was once thought to be a form of multiple sclerosis (MS)**. Also, NMO is becoming more effectively diagnosed with special imaging methods and other new diagnostic criteria that are supported by a recently developed and specific **blood test**. Many of these tools have emerged in just the past 10 years, so the current published estimates of NMO disease may still be lower and may not accurately reflect the true frequency of NMO worldwide.

Currently, NMO in the United States is estimated to affect approximately **1 in 25,000** people (previously published studies cited 1 in 100,000), and seems to occur at roughly this frequency around the world. Global statistics on the prevalence of NMO has yet to be determined¹. In the U.S., the National Institutes of Health

¹Estimates may vary depending on ethnicity.



(NIH) classifies NMO as a rare orphan disease (fewer than 200,000 people affected). **It is estimated that NMO affects at least 4,000 people in the U.S. alone. Worldwide, NMO is likely to affect tens of thousands of people based on prevalence rates in other countries.**

NMO is one of roughly **7,000 rare diseases** that affect about **25 million people in the U.S. alone**, according to the NIH. Each touches a relatively small

population, making it difficult to recover research costs of developing treatments. Rare diseases are commonly called **orphan diseases** because they have not been adopted by the pharmaceutical industry, perhaps due to little financial incentive to make or market new medications to treat or prevent it. **However, NMO is special even among rare diseases, because there is a simple blood test that can enhance diagnosis and specific treatment of NMO as compared with other similar illnesses.**

While a diagnosis of NMO can be challenging, it can also reveal strengths. When presented with their teenage daughter's diagnosis of NMO, the Guthy-Jackson family set out on a mission for all those affected by this uncommon disease to facilitate improved prevention, diagnosis, treatment, and coping resources for NMO patients and caregivers, and to bring scientists and clinicians together to explore new ways to solve this disease.

The Guthy-Jackson Charitable Foundation (GJCF) is a non-profit 501(c)(3) organization dedicated to funding research, increasing public health education, and bringing physicians and researchers together to develop clinical programs with the goal of finding a cure for NMO.

To facilitate **research, education, and outreach**, the GJCF has assembled scientific and medical advisory teams that have identified and published best current

treatment guidelines, recognized expert clinical centers for NMO treatment, and funded basic and clinical science to further the understanding and improve diagnosis and treatment of NMO. The GJCF promotes collaboration among scientific, clinical, industry, and regulatory partners to accelerate new medical solutions and ultimately find a cure for this rare disease.

NMO patients and their blood relatives are invited to talk to their clinicians and medical teams about the possibility of volunteering to participate in **clinical trials**.



NMO

Explained

NMO Explained

- I.1 What is NMO?
- I.2 What are the types of NMO?
- I.3 What causes NMO?
- I.4 What are the symptoms of NMO?
- I.5 What can I expect?
- I.6 How is NMO diagnosed?
- I.7 Diagnoses other than NMO
- I.8 Recognizing a relapse (attack)
- I.9 Areas of the body commonly affected by NMO
- I.10 How does NMO affect the body?
Mechanisms of damage

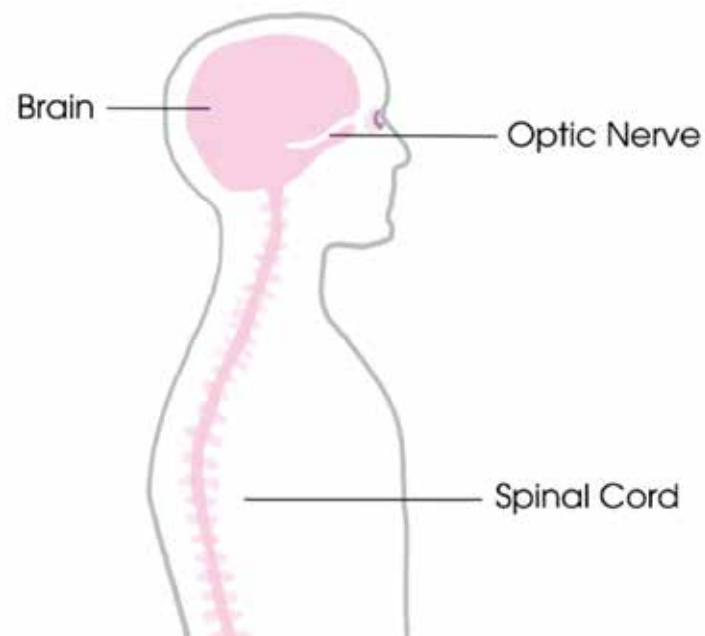
I.1 What is NMO?

Once thought to be a variation of multiple sclerosis (MS), **neuromyelitis optica (NMO)** and **neuromyelitis optica spectrum disease (NMOSD)** are **rare orphan diseases** that are now widely recognized as diseases that occur when part of the immune system dysfunctions, making proteins (antibodies) that attack otherwise healthy parts of the nervous system. In NMO, the attack is directed toward the nerves of the eyes and other parts of the **central nervous system (CNS)**, which include the brain and spinal cord.

QUICK READ

Neuromyelitis optica (NMO) and **NMO spectrum disorders** (NMOSD) are diseases that damage tissues of the **central nervous system** (CNS). These conditions likely result from mistakes made by the immune system that cause injury and swelling (**inflammation**) of the optic nerve (**optic neuritis** or ON) and/or spinal cord (**transverse myelitis** or TM). The first symptoms of NMO are often rapid changes in vision, balance, and/or numbness or weakness of the feet, legs, arms, or hands. These symptoms may improve, but can reappear (**relapse**) and may worsen over time.

NMO and NMO spectrum disorders are inflammatory demyelinating diseases of the CNS characterized mainly by attacks (relapses) of inflammation in both the **optic nerve (optic neuritis or ON) and spinal cord (transverse myelitis or TM)**. Demyelination is a process that erodes away the myelin sheath (the protective covering that surrounds the optic nerve and spinal cord). Damage to the myelin sheath slows or stops impulses traveling along that nerve and may affect many physical systems. Some patients diagnosed with NMO may also have attacks that affect certain parts of the brain, especially the part of the brain that connects to the spinal cord called the brain stem.



Approximately **60 – 70 percent** of NMO patients have detectable antibodies (immune proteins) in their blood that target a protein that channels water in and out of cells existing primarily in the brain and spinal cord called **aquaporin 4 (AQP4)**.

Historically, NMO was diagnosed when both the spinal cord and optic nerves were affected. **Neuromyelitis optica spectrum disorder (NMOSD)** includes limited versions of the condition involving attacks to just ONE area (either ON or TM) with or without the AQP4 antibody. Patients with NMOSD are thought to have a similar prognosis and require similar treatments as do those with fully developed NMO. However, research continues to move forward, making it likely that diagnostic and therapeutic approaches to NMO and NMOSD

will be further refined. Other conditions might also be considered as being within the definition of NMOSD. For example, inflammation of the brainstem that leads to uncontrollable hiccups and vomiting may or may not be caused by NMO or NMOSD. **The classification and diagnostic criteria regarding NMO and NMOSD are anticipated to evolve as new insights are gained and applied to patient care.**

For simplicity in this guide, the abbreviation NMO will be used to mean both NMO and NMOSD.

1.2 What are the types of NMO?

QUICK READ

There are two classically described forms of NMO:

1. Relapsing NMO
2. Monophasic NMO

- **Relapsing NMO** is most common and identified by recurrent attacks months or years apart, followed by partial or complete recovery during periods of remission. **This relapsing form of NMO primarily affects women at an estimated rate of 4:1 compared to men.**

- **Monophasic NMO** is less common and is characterized by a single, severe attack extending over a short period (days or weeks), typically affecting both optic nerves and the spinal cord. Women and men are more equally affected by this type.

When a patient is first diagnosed it remains unclear whether the patient will pursue a monophasic or relapsing course.

1.3 What causes NMO?

QUICK READ

The cause of NMO is unknown. Like many autoimmune conditions, NMO is likely caused by a combination of factors, and may be caused by different factors in different patients. Some of the factors being studied for potential contributions to NMO include:

- Genetics
- Co-existing Autoimmunity
- Infection or Vaccination
- Metabolic Disorders
- Endocrine Disorders
- Allergies
- Other Environmental Factors

Experts do not know the causes of NMO, and there is no specific evidence to inform what may trigger NMO relapses. However, the factors listed in the following pages are being studied for their potential roles in this disease.

Genetics: Changes in structure or function of one or more genes are likely to contribute to NMO disease. However, genetic changes may be present at birth, or acquired over the course of one's life. Recent studies suggest that compared to Caucasian populations, people of Asian or African ancestry have a higher tendency to develop NMO. However in North American and European countries, a majority of cases are Caucasian. Current research does not suggest heritability as a primary cause of NMO, or more common among relatives of NMO patients. **Worldwide, only about 20 families with more than one case of NMO have been reported.** While heredity may play a role, further research is needed to understand what genetic factors (if any) may contribute to NMO.

Sometimes patients with one kind of autoimmune disease also develop additional autoimmune diseases, and this may be true for NMO.



Co-Existing Autoimmunity: NMO is an autoimmune disorder. This means that the body's own defense system (immune system) attacks its tissues and organs. In other words, the body turns on itself and causes disease. In NMO, the immune system is believed to target the aquaporin-4 protein that is present on cells called **astrocytes** in the central nervous system (CNS). At the present time, researchers believe that loss of the myelin sheath that protects nerves (a process called **demyelination**) results from long-term inflammation caused by damage to astrocytes. Sometimes patients with one kind of autoimmune disease also develop additional autoimmune diseases, and this may be true for NMO. Approximately one-quarter of patients with NMO, especially those with a positive blood test for AQP4 antibodies (see section 1.6), have other autoimmune diseases as well, such as systemic lupus



erythematosus, Sjögren's syndrome, autoimmune thyroid disease or myasthenia gravis.

Infection or Vaccination: The causes of NMO are currently unknown. There are many possible **triggers** of NMO disease, but there is still no evidence to prove any specific causes. However, NMO researchers are open-minded to all possibilities for understanding how NMO develops in a given patient. For example, it is possible that the initial causes of NMO and the triggers of NMO relapse may not be identical, and may be different from

patient to patient. In concept, such causes are likely complex, and could include many factors, including patient genetics, diet, hormone status, vaccines, microbial flora or infections, emotional stressors and many more. Studying the potential causes of NMO in a careful and evidence-based manner is the most responsible way to find meaningful answers, and a key mission of the GJCF.

It is important to note that vaccination remains among the most effective ways to prevent many serious medical conditions, and the benefits of immunization programs may far outweigh any known risks. Even so, vaccines are best considered for each person with respect to their specific needs and medical history. As with all information in this guide or elsewhere, **NMO patients or anyone considering vaccination should consult with their physician or NMO specialist to assess the potential benefits or risks of recommended vaccines.**

Metabolic Disorders: In recent years, certain autoimmune conditions have been found to be associated with metabolic disorders. For example, type-1 diabetes is believed to be due to an autoimmune process in which the immune system attacks cells in the pancreas that make insulin. It is possible — but not known — that NMO may arise from a process that involves **metabolic dysfunction**. Some researchers believe that certain foods or sugary diets can contribute to a general increase in **inflammation in the body**. One interesting area of current research focuses on food

components such as gluten as potentially contributing to NMO or other autoimmune diseases.

Endocrine Disorders: NMO and most autoimmune diseases occur at a **much higher frequency in women than men**. This fact suggests there are unique aspects of gender that may contribute to autoimmune diseases, including NMO. For example, **hormones that differ in females and males** can influence the immune system, particularly during a woman's child-bearing years. Likewise, pregnancy can alter immune system function. Research is in progress to better understand potential relationships among gender, hormones, pregnancy (see section 3.4), and NMO onset or relapses as compared to other related autoimmune conditions.

Allergies: Overly active immune system responses are involved in autoimmune diseases as well as allergies. It is possible that there may be a common factor connecting these two conditions, which may contribute to NMO onset or relapse. This area of research is a focus of studies that are currently ongoing.

Other Environmental Factors: In addition to the possibilities previously described, there may be other environmental factors that contribute to the risk of NMO onset, relapse, or severity. For example, the potential roles of stress (physical and emotional), fatigue, temperature, geography, environmental pollutants or toxins, and other factors may be examined for potential correlates to NMO.

I.4 What are the symptoms of NMO?

QUICK READ

General symptoms of NMO are:

- Optic neuritis (ON)
- Transverse myelitis (TM)

The precise symptoms of NMO often vary from person to person. However, NMO is most commonly characterized by one or more episodes of **optic neuritis (ON)** and/or **transverse myelitis (TM)**.

Generally, NMO symptoms begin rapidly. After the initial attack, **NMO follows an unpredictable course**, and **remission intervals vary**. Recurring episodes of optic neuritis and/or transverse myelitis can be weeks to years and on rare occasions, decades, with no treatment in between. Often these symptoms are temporary and resolve (or recover) partially, usually after a course of treatment.

Symptoms and signs of optic neuritis (ON) include:

- Rapid onset of eye pain that is worsened by eye movement
- Impaired or complete loss of vision usually in one, but occasionally in both eyes

- Reduced color vision and depth perception
- Occasionally, swelling of the optic disk (located at the back of the eye where the optic nerve is connected) may be detected, which also can cause “eye pain,” visual changes, and headaches



Symptoms of transverse myelitis (TM) include:

- Pain in the neck or back
- Band or tightness or corset-like sensations in the arms, legs, or stomach
- Sensitivity to touch, cold and heat
- Feeling of numbness, tingling, coldness, itching or burning at the affected level of the spinal cord, often spreading to large parts of the body over a period of minutes, hours or occasionally days
- Weakness in arms or legs ranging from mild to complete paralysis in one or both arms and legs
- Urgent need to urinate or difficulty urinating; urinary or bowel incontinence (unintentional passing of urine or stools), or constipation
- Constipation due to bowel paralysis leading to vomiting, abdominal bloating, pain and inability to pass stool or gas
- Muscle spasms that may last for several minutes accompanied by arm or leg pain
- Fever in some cases

In cases of brain stem or brain involvement symptoms may include:

- Prolonged hiccups, nausea, vomiting or dizziness
- Mental confusion

1.5 What can I expect?



QUICK READ

NMO patients can expect any of the following:

- Acute attacks of ON or TM
- Rapid development of symptoms
- Potential plateau of symptoms
- Symptoms may improve over weeks and/or months with treatment

NMO is considered an acute disease because it **comes on suddenly, lasts a short time** and **may enter a remission**. Progressive disability developing over months and years is unusual, although individual attacks

may not be recoverable leaving severe neurological disabilities that are permanent.

NMO symptoms may develop quickly — **even within a few hours** — increase over the course of a few days and then plateau; symptoms may improve over weeks and months with treatment. Lasting signs and symptoms of NMO vary according to:

- The severity and degree of recovery from the first attack
- The number and frequency of subsequent relapses
- The effectiveness of therapies
- Other co-existing autoimmune disorders, if they are present or develop
- Gender
- Age
- Pregnancy
- Other factors

Depending on the response to therapy, some patients will experience multiple attacks of ON and/or TM throughout their lives. **Some measure of improvement may occur, but patients may experience residual symptoms or disabilities that persist.** Experts estimate that among patients with relapsing NMO, roughly 50 percent will have a

The intervals between relapses are highly variable and unpredictable, but can be managed by adjusting medications that prevent relapse.

relapse in the first year, 75 percent by the third year and 90 percent by the fifth year. **The intervals between relapses can be highly variable and unpredictable, but may be managed by adjusting medications that prevent relapse.**

Relapses can be spaced months or years apart. Although the majority of patients with NMO have the relapsing form of the disease, early diagnosis and treatment may reduce the relapse rate, or lessen the severity of relapses should they occur.

People with monophasic (single attack) NMO, which is much less common than relapsing NMO, tend to have more severe attacks than those with the relapsing NMO; approximately 20 percent of patients have permanent vision loss, and 30 percent have permanent paralysis in one or both legs. **In order to be classified as monophasic, patients experience a single attack of NMO.** Experts are continuing to refine the specific definitions of NMO and NMOSD

to most accurately determine the best clinical care. As previously stated, for simplicity in this guide, the abbreviation NMO will be used to mean both NMO and NMOSD.

1.6 How is NMO diagnosed?

QUICK READ

NMO can be diagnosed by a combination of the following methods:

- Magnetic Resonance Imaging (MRI)
- Neurological examination
- Blood test: NMO-IgG
- Lumbar puncture (spinal tap)
- Eye tests

The defining features of NMO are transverse myelitis (TM) and optic neuritis (ON) with at least two of the following characteristics:

- Magnetic Resonance Imaging (MRI) results which are not diagnostic for MS
- A spinal cord lesion extending over three or more vertebral segments
- Presence of aquaporin-4 antibody (NMO-IgG) in the blood

A diagnosis of NMO begins with medical history, questions about signs and symptoms and a neurological examination. Key elements of diagnostic testing include:



Magnetic Resonance Imaging (MRI)

MRI is a vital tool in diagnosing NMO. This **generally safe and painless test** uses strong magnetic fields and radio waves to produce a detailed **image of the brain and spinal cord**.

Patients are placed on a table that slides into a cylinder. Most imaging centers offer headphones with a wide assortment of music and eye covers for comfort. Some centers have open MRI scanners (no cylinder) that are helpful for patients with claustrophobia. The procedure **lasts approximately 30 to 60 minutes** and requires the **patient to be still** the entire time. Often a water-based dye is injected into an arm vein (through an IV

or intravenous catheter) just prior to the scan. This dye allows for more specific pictures of the lesions or sites of inflammation in the brain, optic nerves and spinal cord and is flushed out of the body within a few hours. Generally MRI test results in NMO patients show **lesions** indicative of inflammation that extend over three or more segments of the spinal cord, the optic nerve(s) and occasionally in the brain. However, brain lesions observed in NMO follow a different pattern and are not as common as in other diseases, including MS.



Neurological Examination

A neurologist examines a patient's cognitive (thinking) function, vision, speech, muscle strength, reflexes, coordination and sensation. An eye specialist also may be involved in the examination to look for swelling or inflammation in the optic nerves.



Blood Test – NMO-IgG

In the blood of NMO patients, a particular **antibody** (a type of protein produced by a type of immune system cells called B-cells) is present. This antibody can attack the **aquaporin 4** water channel protein present on the astrocyte cells of the brain. The blood test is known as **NMO-IgG** (NMO Immunoglobulin G – sometimes referred to as “**AQP4 antibody**”). **Its detection strongly supports a diagnosis of NMO.**

However, not all patients with NMO have a positive NMO-IgG test. Someone may test negative for NMO-IgG, but still have NMO. It is possible that NMO-IgG may not be detectable with the current tests available. Newer tests are being developed that have a higher rate of detecting the NMO-IgG antibody. Also, some patients may have undetectable antibody levels due to treatment they are receiving.

It is possible that some people may have a different, currently unknown, antibody that can produce similar effects as NMO-IgG.

The **NMO-IgG test can be ordered by any physician** and is generally ordered by a patient’s primary care physician or neurologist.



Lumbar Puncture (spinal tap)

If your **blood test for NMO-IgG is negative** and your diagnosis is unclear your neurologist may suggest a lumbar puncture or “spinal tap” for further testing.

The lumbar puncture allows the neurological team to test the **cerebrospinal fluid (CSF)** surrounding the brain and spinal cord, and observe the levels of immune cells, proteins and antibodies in the fluid. In NMO, the

In NMO, the spinal fluid may show considerably elevated white blood cells during attacks.

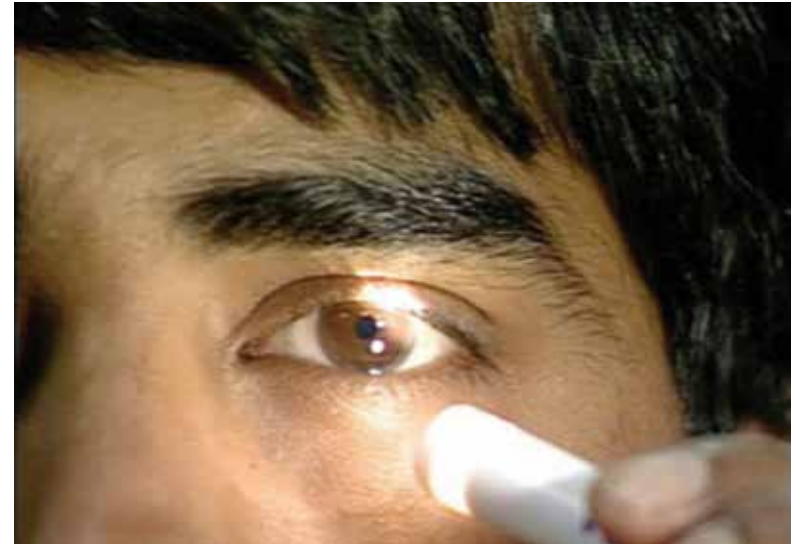
spinal fluid may show considerably elevated white blood cells during attacks, which are greater than typically seen in other autoimmune diseases. In differentiating these conditions CSF is tested for oligoclonal bands (proteins), which is commonly detected in patients with MS, and is usually, but not always, negative in patients with NMO.

Ophthalmological Tests

To help obtain a correct diagnosis, patients may be referred to an ophthalmologist or eye specialist. The ophthalmologist may perform the following eye tests:

- **A routine eye exam** will check vision and the ability to perceive different colors and depth perception.
- **Ophthalmoscopy** examines the structures at the back of the eye by shining a bright light into the area. This eye test evaluates the optic disk, which is the area where the optic nerve enters the retina in the eye. The optic disk becomes temporarily swollen in about one-third of people with ON. Patients who

have had previous optic neuritis due to NMO may have a permanently pale optic disk, but the same may occur in patients with MS and other conditions that target the optic nerve, therefore this is not a specific finding for NMO.



- **Pupillary light reaction** tests the eyes to see how pupils respond when exposed to bright light. After shining a bright light in a healthy eye, the pupil of the eye affected by ON often incorrectly dilates.
- **Optical coherence tomography (OCT)** is a non-invasive image technique to study the retina. OCT is a simple high-resolution scan used to measure the thickness of the retinal nerve fiber layer (RNFL). The RNFL is often decreased in NMO patients with optic neuritis.

1.7 Diagnoses Other Than NMO



QUICK READ

NMO can have signs and symptoms similar to:

- Multiple sclerosis (MS)
- Acute disseminated encephalomyelitis (ADEM)
- Sjögren's syndrome
- Systemic lupus erythematosus (SLE)
- Mixed connective tissue disease (MCTD)
- Viral infection
- Sarcoidosis

With so many symptoms that are very similar to those of multiple sclerosis (MS), lack of NMO diagnosis can be a missed opportunity to treat the disease in its earliest

form. Conditions commonly confused with NMO that can produce optic neuritis and myelitis include:

- **Multiple sclerosis (MS):** an inflammatory condition of the central nervous system (CNS) affecting movement and balance. **Optic neuritis and myelitis are common in MS, although less severe than in NMO.** MS generally has a slower, longer course than NMO. **Thus far there is no blood test to diagnose MS, like there is to diagnose NMO.**
- **Acute disseminated encephalomyelitis (ADEM):** a short-term condition affecting the brain and spinal cord, which can also cause optic neuritis and myelitis.
- **Sjögren's syndrome:** an autoimmune condition affecting the saliva and tear glands.
- **Systemic lupus erythematosus (SLE):** an autoimmune condition causing joint pain, fatigue, rashes, kidney disease and sometimes inflammation in the CNS.
- **Mixed connective tissue disease (MCTD):** inflammation of the connective tissue.
- **Infection:** inflammation caused by an infection of the central nervous system (CNS).
- **Sarcoidosis:** a type of inflammation that may target multiple organs including the optic nerves, brain and spinal cord.

FACTS ABOUT NMO AND MS

Until recently, NMO was thought to be a type of MS. However, recent discoveries indicate that NMO and MS are distinct diseases.

With so many symptoms in common, NMO can sometimes be confused with MS or other diseases. But these diseases are treated in different ways and early detection and treatment help ensure best outcomes.

NMO symptoms may include:

- Severe, rapidly deteriorating attacks
- Episodes of nausea, vomiting or hiccups
- Usually normal MRI brain scan early in disease
- Distinct long spinal cord lesions
- NMO-IgG presence in blood

MS symptoms may include:

- Initial attacks usually relatively milder
- MRI usually shows abnormalities with a classic pattern

◆ **Some MS medications do not help NMO patients and may actually cause more severe attacks and complications**

1.8 Recognizing a Relapse (Attack)

Mimicking the initial attack, a patient can experience a recurrence of similar symptoms due to inflammation of the optic nerves and spinal cord as outlined in section 1.4. This effect is sometimes referred to as “ghost” or residual pain following an attack. It is important to determine whether such symptoms represent a new relapse, or the after-effects of a prior attack.

Maintaining regular communication with your healthcare team, and seeing your physician or neurologist immediately if there are unresolved symptoms is best in this regard.



I.9 Areas of the Body Commonly Affected by NMO



QUICK READ

NMO occurs when a part of the immune system (which is supposed to keep a person free of infections and disease) dysfunctions, making antibody proteins that attack otherwise healthy parts of the nervous system causing neurological problems.

Areas of the body:

- Nervous system
- Blood brain barrier (BBB)
- Astrocytes
- Immune system

Nervous System

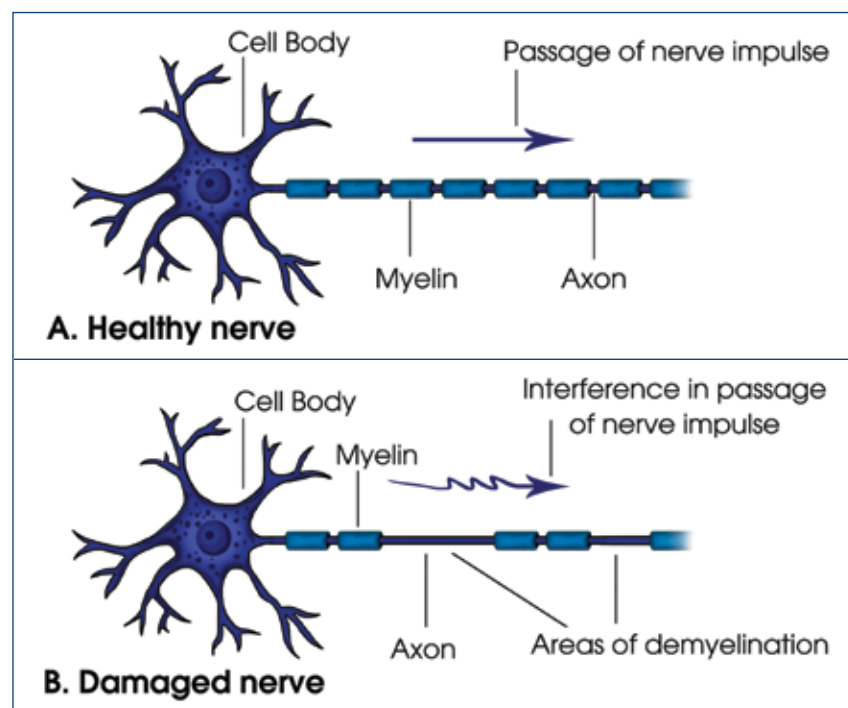
The nervous system regulates all body activity including: memory, language, vision, mobility and sensation. It includes the brain, spinal cord, optic nerves and a circuitry of nerve cells (called **neurons**) responsible for transmitting information to and from all parts of the body. Other specialized cells known as astrocytes and glial cells physically support the neurons.

The nervous system is comprised of the **central nervous system (CNS)** and the **peripheral nervous system (PNS)**. The spinal cord, optic nerves and the brain make up the CNS. They coordinate the activities between the various parts of the body. The PNS is the portion of the nervous system outside

the brain and spinal cord. The PNS carries incoming messages to the CNS from sensory organs (such as the eyes, skin, and ears), and carries messages from the CNS to muscles, sweat glands and blood vessels.

The spinal cord and optic nerves are the main sections of the nervous system affected by NMO.

The spinal cord controls movement, receives sensations and regulates bodily excretions and secretions. The optic nerve carries visual information from the eye to the brain.



Nerve Conduction

Neurons are the basic information processing units in the CNS. They receive, process and send information

to other neurons through cable-like fibers called **axons** using charged particles.

Axons help process signals in the nervous system. For example, in the case of light stimulation, the eye interprets the signal via the retina, which contains special sensors that convert light energy to molecules. Next, the molecules activate neurons in the optic nerve, which then transmits the information to the brain. Similarly, in the case of pain stimulation, sensory information is carried from the nerve endings in skin to the spinal cord and brain.

Axons are coated by a fatty substance called the **myelin sheath**, which plays an important role in speeding and securing electrical transmission along axons. This sheath allows impulses to transmit efficiently along the nerve cells (like a conduit in an electrical system), ensuring messages sent by axons are not lost en route to the spinal cord, muscles or internal organs. **If myelin is damaged, the ability of neurons to transmit signals slows down or stops altogether.**

Blood-Brain Barrier (BBB)

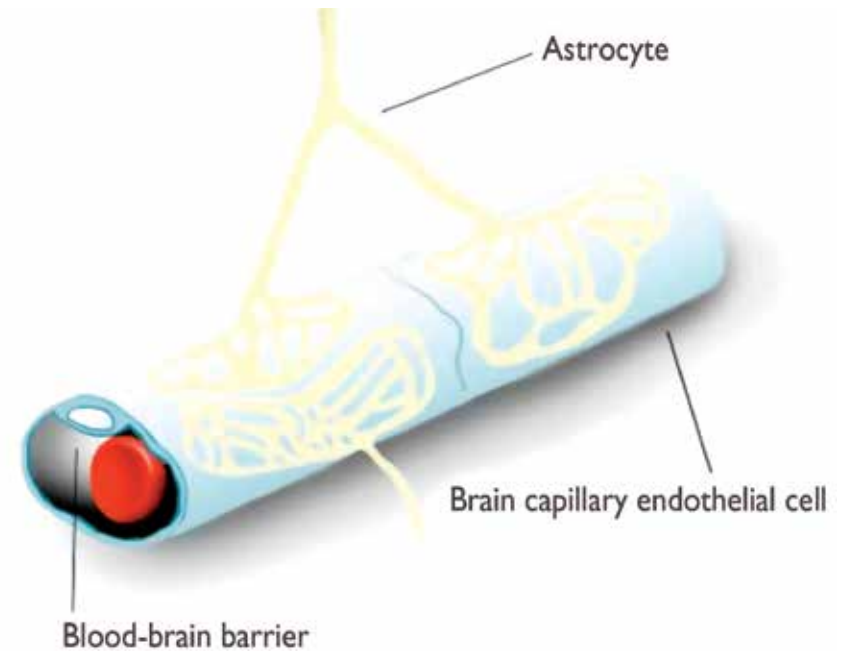
The Blood-Brain Barrier (BBB) is a complex of cells and specialized junction proteins that connect where the central nervous system (CNS) tissues meet the blood vessels (capillaries). It creates a filter to the CNS, separating the circulating blood and its chemical and cellular components from the CNS. The barrier prevents

some drugs, chemical compounds, radioactive ions, and disease-causing organisms contained in the blood from passing into the CNS. **The BBB helps protect the CNS from potentially harmful elements circulating in the blood.** Only special cells and substances that provide food and function to the brain are allowed through the barrier. Some parts of the BBB are naturally more permeable (or easy to pass through), and **it seems as if the NMO-IgG antibody has a particular tendency to attack the brain at these more vulnerable sites of the BBB.**



Certain injuries, drugs and other diseases may lead to breakdown of the BBB. When this happens, substances normally kept out of the brain are able to pass through the walls of the vessels into the brain.

Astrocytes



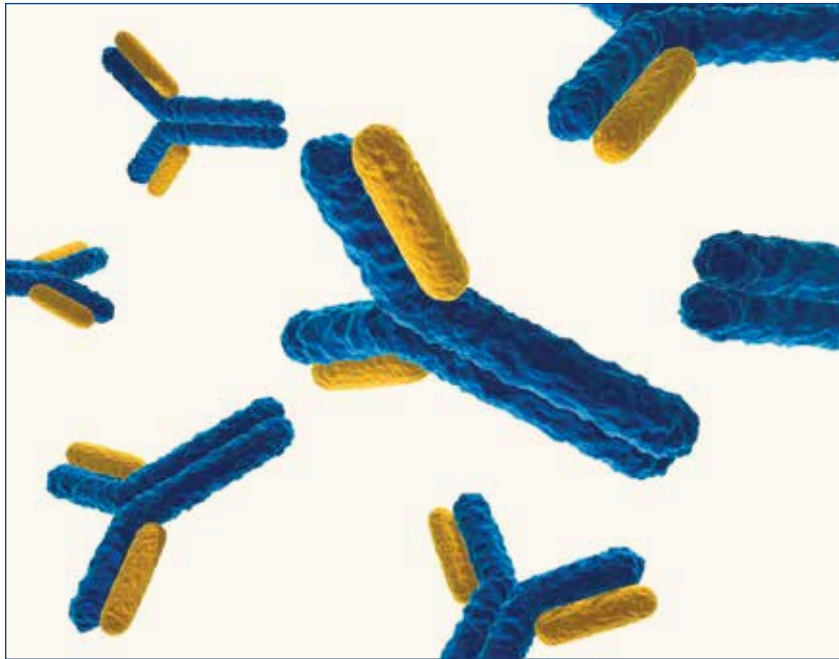
Astrocytes are the most abundant cells in the CNS and play a key role in the function of the BBB. They have several functions, including to serve as a framework guiding neurons to their proper locations during development, and support the BBB in maintaining a “privileged” environment unique to the CNS.

Astrocytes make other significant contributions to neuron activity including coordinating electrical signals for proper brain function and providing nutrients to the nervous tissue.

Astrocytes also support water transport in the CNS through the pores on their surface. The pores produce pathways through which water flows in the cell – this is known as the aquaporin-4 (AQP4) water channel.

In NMO, AQP4 is the target of NMO-IgG antibodies. By attaching to the water channel on the astrocyte, the antibody activates inflammatory proteins, such as complement, and attracts inflammatory cells. This leads to many secondary consequences by killing some astrocytes and disrupting the normal functions of others. **These events may produce the symptoms of an NMO attack.**

The Immune System



Antibodies

NMO is believed to occur when the immune system attacks one's own tissues as if they were foreign.

One of the most important functions of the immune system is to defend the body from external threats such as microbes, or internal threats such as cancer. The ability to tell the difference between healthy cells and tissues, and those representing infective or cancer threats is key. The ways in which the immune system achieves this goal are complex. Simply put, the immune system **T and B cells** (also called **lymphocytes**) are responsible for detecting self (normal) and non-self (abnormal) molecules or cells. **B cells** are named for their maturation in the **Bone marrow**, while **T cells** mature in the **Thymus**. When a foreign or abnormal cell is detected by these cells, immune reactions are triggered. This step leads to activation of the specific type of **T and B cells that first recognized the abnormal signal, and reproduction of these cells. Over time, these T and B cell lineages lead a coordinated immune response to specifically remove the foreign or abnormal target, such as the invading microbe or cancer cell.**

Most of the time the immune system is amazingly accurate in detecting foreign or abnormal cell threats and signals. However, in autoimmune diseases, this process goes wrong: T, B or other immune system cells mistake normal cells or tissues as foreign or abnormal.

NMO is believed to occur when the immune system attacks one's own tissues as if they were foreign. Some parts of the immune system include the thymus and spleen, in which T cells and antibody-producing B cells protect the body from the development of infection and other diseases. Normally in this process, immune cells with abnormal function that mistakenly react to normal cells or tissues are deleted to prevent autoimmune diseases. However, this is not a fool-proof editing system, and certain auto-reactive (or autoimmune) cells may survive and contribute to autoimmune disease.

The ability of the immune system to recognize and ignore self tissues as being normal is called **immune tolerance**. When this normal protection against autoimmunity breaks down, the immune system reacts to self cells or tissues, and mistakenly attacks the body. This is known as an autoimmune disease, or a disease where the body mistakes itself for a foreign or abnormal threat.

This misdirected immune response — autoimmune disease — can cause a broad range of illnesses. In NMO, most patients have antibodies in their blood that target an ordinary protein of the CNS, AQP4.

I.10 How does NMO affect the body? Mechanisms of Damage

QUICK READ

In NMO, damage can affect the body if:

- The immune system mistakenly produces harmful AQP4 antibodies.
- The Blood Brain Barrier becomes disrupted.
- Complement proteins contribute to intense tissue destruction and attract other inflammatory cells.
- More complications arise in the body.

Inflammation

Inflammation is the first response of the immune system to injury or infection. For example, a cut to the skin will almost always result in inflammation, as will an infection. Inflammation is a vital defense mechanism essential for survival. Without inflammation, the body would not clear out harmful substances and allow normal tissue to rebuild. **In NMO, the harmful substances are the AQP4 antibodies mistakenly produced by the immune system.**

If the blood-brain barrier (BBB) which normally protects the CNS is disrupted or “opened” (see section I.9), and AQP4 antibodies cross in, they can attach to the

In NMO, the harmful substances are the AQP4 antibodies mistakenly produced by the immune system.

AQP4 protein on the astrocyte. In turn, this can send molecular messages to other white blood cells to attack the astrocyte. At the same time, another family of inflammatory proteins (called the **complement system**) is activated. Complement is a collection of over 20 proteins that work together and normally help other immune system cells to clear infection, kill cancer cells, or promote wound healing. In the case of NMO, complement proteins can contribute to intense tissue destruction and attract other inflammatory cells, including special types of white blood cells called **granulocytes** (such as **neutrophils** and **eosinophils**) and **macrophages**.

Demyelination

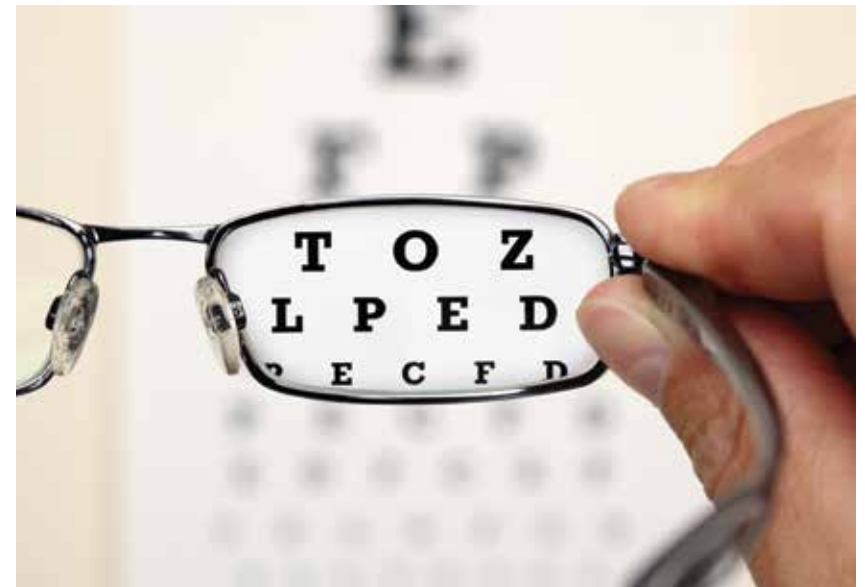
When the AQP4 antibody interferes with the transfer of water in the brain, water accumulates in the myelin sheath (protective insulation surrounding nerves), causing nerve conduction to slow. This breakdown of myelin is known as demyelination.

The combination of inflammation and demyelination can cause damage to nerve tissue but may be reversed with early treatment.

Symptoms of Mechanisms of Damage

Optic Neuritis

Optic neuritis (ON) is inflammation of the optic nerve, which carries visual information from the eye to the brain. In NMO, ON may involve either one or both optic nerves. **Optic neuritis is the most common and often initial symptom in NMO.** It is characterized by eye pain, vision loss and optic nerve dysfunction. Inflammation causes loss of vision usually because of swelling and destruction of the myelin coated neurons. The visual loss may be subtle or profound.



Transverse Myelitis

Inflammation across an elongated segment of the spinal cord is known as transverse myelitis (TM). The term “transverse” describes the position of inflammation. Transverse may mean “cross section,” however in neurological usage, **transverse** usually refers to abnormal imagery along an extended section of the spinal cord. “Myelitis” refers to inflammation of the spinal cord. In NMO, TM extends over three or more spinal vertebrae (longitudinally extensive). The part of the spinal cord where the damage occurs determines which parts of the body are affected.

- Nerves in the **cervical** (neck) area control signals to the neck, arms, hands and breathing muscles (diaphragm).
- Nerves in the **thoracic** (upper back) area send signals to the torso and some parts of the arms.
- Nerves at the **lumbar** (mid-back) level control signals to the hips and legs.
- **Sacral** nerves, located within the lowest segment of the spinal cord, relay signals to the abdomen, groin, toes, and some parts of the legs.

Damage at one segment of the spinal cord will affect function at and below that segment. Pain in the lower back is a symptom of TM. Demyelination usually occurs at the upper back thoracic level, causing problems with leg movement, bowel and bladder control, skin numbness, tingling or pain.

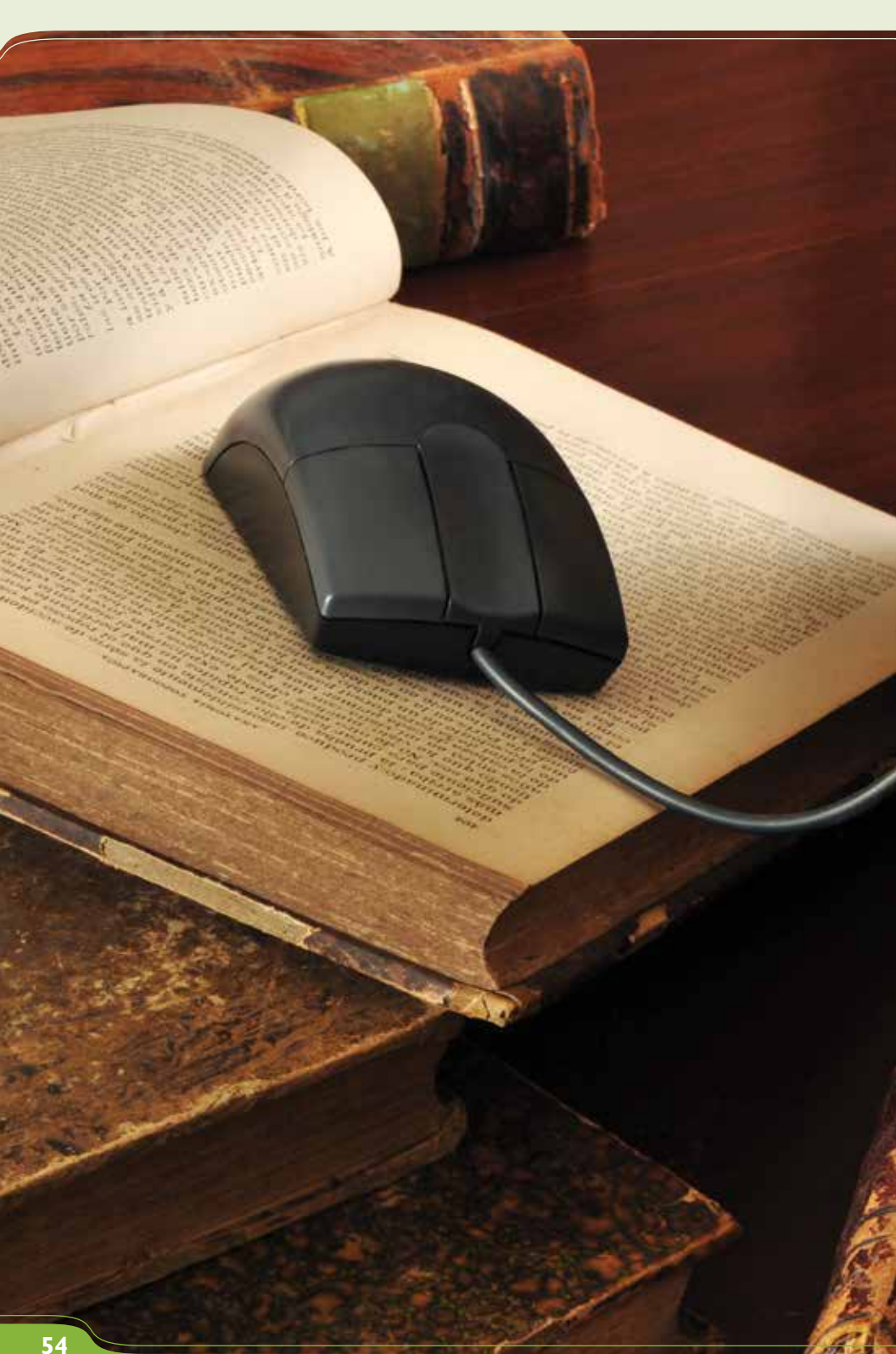


Do you know?

NMO patients can join an email list or visit our Facebook and Twitter pages to receive information and get updates about NMO clinical trials. See Sections 5 & 6 to find out more.



History & Discovery



History & Discovery

- 2.1 Who first described NMO?
- 2.2 What is the difference between NMO and Multiple Sclerosis?
- 2.3 How common is NMO?
- 2.4 Who is affected by NMO?

2.1 Who first described NMO?



QUICK READ

- 1804: Dr. Antoine Portal publishes an early case of disease consistent with NMO.
- 1870: Sir Thomas Allbutt, M.D. initially describes a case of simultaneous optic neuritis and transverse myelitis that does not have obvious brain tissue involvement.
- 1894: Eugène Devic, M.D. coins the term “neuromyéélite optique,” or neuromyelitis optica.
- 2006: Vanda A. Lennon, M.D., Ph.D. and colleagues at the Mayo Clinic identify the NMO-IgG antibody as being correlated specifically with NMO disease.



Eugène Devic

In 1804, **Dr. Antoine Portal** described a special case of ON / visual loss / spinal cord inflammation in the absence of brain pathology which may likely be the first report of “NMO” disease. In 1870, a British physician scientist named **Sir Thomas Allbutt** is given credit for initially describing a case of simultaneous optic neuritis and transverse myelitis. Later in 1894, a French neurologist named **Eugène Devic** published a case series of 16 such patients and coined the term

Devic’s disease and NMO are different names for the same condition, with NMO being the contemporary term.

“neuromyéélite optique.” Devic’s clinical study of optic neuritis plus transverse myelitis became popularly known as Devic’s disease or Devic’s syndrome.

Devic’s disease and NMO are different names for the same condition, with NMO being the contemporary term used globally by leading clinicians and scientists. When Dr. Devic described the disease, it was characterized by clinical blindness and paralysis. Today, we have newer diagnostic and therapeutic strategies, and patients are increasingly being diagnosed earlier in the disease. Thus, the disabled patients that Dr. Devic described over 100 years ago generally do not present the same advanced level of disability.

With the discovery of the NMO-IgG (see section 1.6) by Vanda A. Lennon, M.D., Ph.D., and colleagues at the Mayo Clinic in 2006, clinicians now have the best chance to detect an NMO diagnosis.

When NMO was initially described it was as a severe, usually monophasic (single event) disorder of the optic nerves and spinal cord and was thought to be a type of multiple sclerosis (MS). **Evidence in the past decade has established NMO as a distinct disease.** NMO is now generally recognized as a recurrent or relapsing disease that largely targets the spinal cord and optic nerves. NMO can affect the brain as well, but generally to a lesser degree than in MS. **While there may be similarities between NMO and MS, one emerging theme is that different medicines may be best to treat NMO as compared with MS.** If so, early detection and accurate diagnosis of both NMO and MS will benefit patients regardless of which disease they may have.

2.2 What is the difference between NMO and Multiple Sclerosis (MS)?

QUICK READ

At times, **NMO symptoms** may include:

- Severe, rapidly deteriorating attacks.
- Episodes of nausea, vomiting or hiccups.
- Usually normal MRI brain scan early in disease.
- Distinct long spinal cord lesions.
- NMO-IgG presence in blood.

Research conducted over the past 10 years suggests that NMO and MS result from different immune system problems, target different cells and tissues, have non-identical signs and symptoms, and patients may have the greatest benefit from different treatments. **The primary differences between NMO and MS are:**

- Patients with **NMO** often experience:
 - **Severe, rapidly deteriorating attacks**
 - **Attacks often result in long-term disability**
- Patients with **MS**:
 - Initial attacks are usually relatively more mild
 - Disability often tends to develop incrementally over time and not as a result of a single attack
- About 10-20 percent of patients with **NMO** may also have episodes of:
 - **Nausea, vomiting or hiccups lasting up to a month**
 - These symptoms are not specific to for NMO, but are not commonly seen in MS

At times, **MS symptoms** may include:

- Initial attacks are usually relatively milder.
- MRI usually shows abnormalities with a classic pattern.



- Patients with NMO usually have normal magnetic resonance imaging (MRI) brain scans (see section 1.6) early in the course of the disease, while the brain scans of patients with MS usually show abnormalities with a classic pattern on MRI. However, newer imaging techniques suggest brain tissue may be involved in NMO disease, and perhaps early in the natural history of disease.
- About 80 percent of patients with NMO have distinct, long lesions in the spinal cord on MRI that are not typically present in patients with MS.
- **An antibody, called NMO-immunoglobulin G (NMO-IgG), is present in the blood of approximately 70 percent of NMO patients.** Patients appropriately diagnosed with MS do not usually test positive for NMO-IgG (see section 1.6).

- NMO and MS are often initially treated with medications that work by changing the immune response.



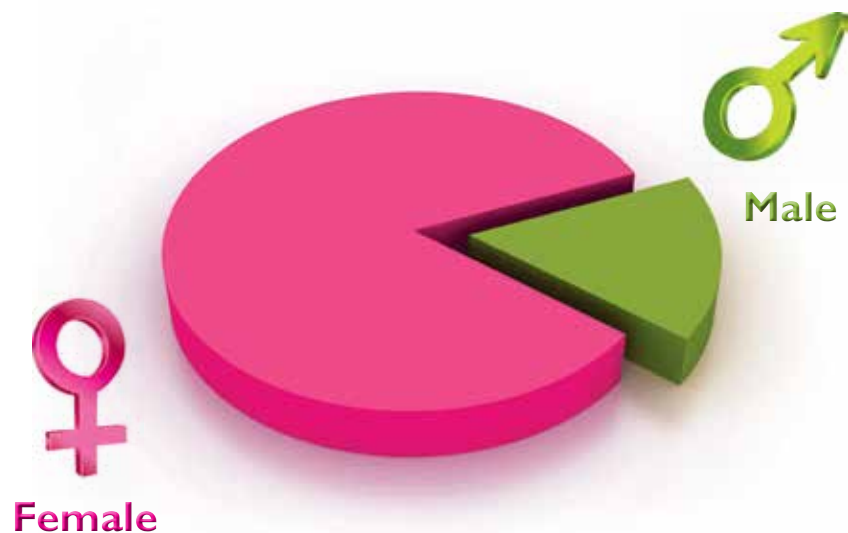
Some MS medications do not help NMO patients and may actually cause more severe attacks and complications.

2.3 How common is NMO?

NMO is a rare condition with few population-based studies available. While estimates may vary depending on ethnic background, currently, NMO in the United

States (U.S.) is estimated to affect approximately 1 in 25,000 people (previously published studies cited 1 in 100,000). In the U.S., the National Institutes of Health (NIH) classifies NMO as a rare orphan disease (fewer than 200,000 people affected). **It is estimated that NMO affects at least 4,000 people in the U.S. alone. Worldwide, NMO is likely to affect tens of thousands of people based on prevalence rates in other countries.** Current, ongoing studies suggest the **incidence** (new cases) and **prevalence** (total active cases) of **NMO are even higher**, due in part to **confusion with closely related conditions such as MS**, lack of awareness in the healthcare community, or underdiagnosis of this rare disease (see section 1.7).

2.4 Who is affected by NMO?



NMO is more common in women than men, with a ratio of approximately 6:1. NMO also appears to be more common among individuals having African, Asian, Pacific Island, or Caribbean ancestry. However, anyone can be affected.

**NMO is more common
in women than men, with a ratio
of approximately 6:1.**

The onset of NMO varies from childhood to adulthood. The median age of onset is between 32 and 40 years of age, based on reports from different regions of the world.

How can I make a difference?

NMO patients and their blood relatives can contribute to research to discover new treatments for NMO by donating small samples of blood (from time to time) to the **GJCF NMO Blood Bank**. See Section 5 to find out how.

Treatment & Management of NMO





Treatment & Management of NMO

- 3.1 Finding an NMO Specialist
- 3.2 Medical Treatment of NMO
- 3.3 Recovering from a Relapse
- 3.4 Pregnancy and Pediatrics
- 3.5 Creating a Healthcare Team
- 3.6 Managing Diet and Nutrition

3.1 Finding an NMO Specialist

QUICK READ

Finding a clinician that you feel comfortable with and confident in is your personal decision. Clinicians specializing in NMO diagnosis or treatment may be viewed by visiting GJCF's **Mapping NMO** online at: www.guthyjacksonfoundation.org/mapping-nmo.

There are several ways to locate an NMO specialist. Physician referrals and word of mouth are two methods. Additionally, The Guthy-Jackson Charitable Foundation

(GJCF) maintains a current online directory of NMO clinicians worldwide. To locate an NMO specialist, visit the foundation's website section called "Connect the Docs" at: www.guthyjacksonfoundation.org/mapping-nmo. To locate an NMO clinician, choose a country and state or province from the drop-down menu.

Other ways to find NMO clinicians are to visit **NMOtion** and **Spectrum**, the foundation's online NMO community resource sections, at: nmotion.guthyjacksonfoundation.org and www.spectrum.guthyjacksonfoundation.org, and the foundation's **Facebook** page at: www.facebook.com/guthyjacksonfoundation.

Mapping NMO is a source of information only. GJCF does not lend endorsement to any clinicians or physicians presented on **Mapping NMO**.

3.2 Medical Treatment of NMO



QUICK READ

Treatment of NMO requires careful diagnosis and consideration by the neurologist and clinical team. Depending on the unique factors of a given case, different approaches may be used to manage different patients. Medical approaches used to help treat NMO can include steroids, plasma exchange (PLEX), immunoglobulins, immune suppression with medications and alternative therapies.

At present there is no definitive "cure" for NMO. Therefore, effective treatment is the focus of clinical care, which may differ from patient to patient. Optimal NMO treatment considers many factors, including:

- Accurate and early diagnosis of NMO and other associated illnesses
- Treating the initial episode promptly and appropriately
- Anticipating or treating relapses quickly and effectively
- Managing any long-term symptoms resulting from relapse
- Minimizing conditions that may trigger future relapses

Managing the First Episode of NMO

The first episode (**incidence**) of NMO can be a confusing and frightening experience. Often times this



episode occurs completely by surprise. Interestingly, recent research has suggested that some cases of **NMO may come after prolonged hiccups, nausea or vomiting, or other seemingly unrelated symptoms.** In some cases, the **first sign of NMO** may be **eye pain** or a **change in vision that comes on suddenly and worsens quickly.** In other cases, **NMO is first noticed as a loss of arm or leg strength, or difficulty in balance.** In every case, **NMO can be a neurological emergency**, and quick actions offer best chances for good outcomes:

- contact your doctor or neurologist immediately;
- go to the closest appropriate emergency room or clinical care center;
- remind the clinical staff to consider NMO as a possible cause of the symptoms (called the **differential diagnosis**); and
- try to be calm and be

In some cases, the first sign of NMO may be eye pain or change in vision that comes on suddenly and worsens quickly.

prepared for blood tests, imaging (e.g. MRI or CT scans), or perhaps a lumbar puncture (see section 1.6). These tests are generally extremely safe, and can be done relatively quickly.

If NMO or another inflammatory condition is detected in the optic nerves or central nervous system (CNS), steroids are normally one of the first medicines to be given. For acute or severe cases, this medicine is given through a vein. The neurologist may admit the patient into the hospital during an acute episode, to deliver IV medications, facilitate diagnostic tests, and provide close observation. Depending on results of blood or lumbar puncture tests, the clinical team may recommend other immediate treatment as well. For example, a process to remove harmful antibodies from the blood may be used, called **plasma exchange** (PLEX). In other cases, addition of potentially beneficial antibodies to the bloodstream may be used, called **intravenous immunoglobulin** (IVIG). The goals of these strategies

Once the initial symptoms are under control, individuals begin their journeys living with NMO.

(described in more detail in the following pages) are to calm any acute inflammation that may be affecting the CNS, including the optic nerves, spinal cord or brain.

Ideally, the rapid response to symptoms of NMO may assist in the best outcome. Once the initial symptoms are under control, individuals begin their journeys living with NMO.

Managing Relapses in NMO

As in the first NMO **incidence** (episode), high-dose steroids classically are usually given during a relapse. Steroids work by calming the immune system and reducing inflammation in the central nervous system (CNS). They are usually given:

- Intravenously (through a vein) for 3-5 days
- Often followed by a course of oral steroids for several months or even as long-term therapy
- Steroid doses are adjusted based on an individual's disease status and/or side effects

If steroids don't help, what next?

Many episodes of NMO respond to steroid therapy. However, **in some cases steroids do not provide clinical benefit.** When attacks progress or do not respond to steroid treatment, **there are other treatment options** that may be considered. These include plasma exchange (PLEX) or use of intravenous immunoglobulin therapy, as described in the following pages.



Plasma Exchange (PLEX) aims to remove the harmful aquaporin-4 (AQP4) antibodies (see section 1.9) and other soluble inflammatory factors from the circulation. Using a specialized technique, blood is drawn out of the body, cells are separated from the plasma and returned to the patient, with the plasma being discarded and replaced. This procedure may be performed using

catheters placed in arm veins, however some patients require a permanent catheter if PLEX is required on a regular basis.

Intravenous Immunoglobulins (IVIG) is administration of a collection of antibodies from a pool of thousands of healthy blood donations to the recipient patient. How IVIG therapy may work is not completely understood; it is believed to add good antibodies and other factors from healthy individuals to act against any harmful antibodies or related factors within NMO patients. The result is that IVIG therapy may help to suppress inflammation.



Long-Term Management of NMO

Long-term management of NMO aims to reduce or perhaps prevent relapses which can cause ongoing or worsening symptoms, and may lead to long-term or permanent damage. Many neurologists use different agents and approaches for this goal. Listed below are a

few of the common treatment options neurologists may consider on a case-by-case basis:



Low-Dose Steroids

In NMO, inflammation caused by the immune system leads to injury to the central nervous system (CNS). For this reason, medicines that calm the immune system are often used to treat NMO. Corticosteroids (often called **steroids** in NMO treatment) are commonly used for this purpose. Steroids calm or suppress the immune system in a general way, or **non-specifically**. Initial or relapse episodes of diagnosed NMO are often treated with **intravenous steroids**. Once the episode is under control, oral steroids are used until other **maintenance treatments** are in place (see the following pages). In some patients, relapses may occur after steroid treatment is gradually stopped. If so, use of low-dose / long-term steroids may be appropriate to help reduce the frequency or severity of relapses. Ideally, your clinical care team may

identify a low-dose of steroid treatment best for a specific NMO case. If so, long-term / low-dose steroid treatment is often referred to as a **maintenance dose** in hopes of reducing the number or severity of relapses.

It is important to note that steroids are powerful medicines that suppress the immune



It is important to note that steroids are powerful medicines that suppress the immune system overall.

system overall, including the body's ability to fight infection. In addition, steroids can have other **side effects**, such as **weakening of the bones**, and **changes in metabolism or weight**.

Long-term side effects of steroid treatment can also include:

- **Weight gain**
- **Acne**
- **Indigestion**
- **Cataracts**
- **Osteoporosis**
- **Diabetes**

In some cases, **antacids** and **tablets for bone protection** (biphosphonates, calcium supplements, and vitamin D) **may be helpful to reduce the side effects of steroids.**

It is also essential to be aware of signs of steroid withdrawal that can be related to tapering off of steroids too quickly. These signs may include:

- **Nausea**
- **Vomiting**
- **Joint aches** (hands and feet especially)
- **Weakness**
- **Fatigue**
- **Low blood sugar**
- **Weight loss**
- **Lack of appetite**
- **Dizziness with standing**
- **Low blood pressure**

Patients experiencing any of these symptoms while on a steroid tapering (or lowering) regimen should notify their physician immediately.

Other Immune Modifying Agents

Aside from steroids, several other treatments may also be considered in managing the long-term treatment of NMO. Many of these agents are intended to reduce the need to take steroids, which can have side effects. For this reason, such treatments are called **steroid-sparing** regimens. Some of these treatment regimens are considered briefly in the following pages. These drugs can be powerful treatments to suppress the immune system, and they all have side effects that are generally well understood. Therefore, each drug would need to be explained and carefully considered by your clinical team. As always, all NMO patients should consult with their physicians or neurologists before taking any medicine.



First-Line Agents

[listed alphabetically]

Azathioprine (Immunan®): this drug is an **immunosuppressant**, available in tablet form for oral administration. It is believed to calm the immune system by reducing the production of cells involved in the immune response.

Mycophenolate Mofetil (CellCept®): like other immunosuppressing drugs, mycophenolate mofetil inhibits the number and function of immune system cells. Mycophenolate mofetil has a more specific target than azathioprine, namely an enzyme that is largely made by T and B cells. However, this action of mycophenolate

mofetil also reduces the ability of the body to fight infections. Mycophenolate mofetil comes as a capsule, a tablet, a delayed-release tablet, and a suspension (liquid) to take by mouth. Some hospitals and physicians use another version of mycophenolate acid called Myfortic®. Sometimes this is given to patients who have gastrointestinal upset from the mycophenolate mofetil.



Rituxumab (Rituxan®): this drug is an example of the **biological** (protein-based) class of drugs that may be considered in NMO treatment. It is an example of using an antibody to treat a disease. Rituximab works by removing a specific type of immune cells (B cells) from blood circulation, which appears to calm the immune system and may help to prevent NMO relapses. Rituxumab is an intravenous medicine, usually given as two intravenous infusions two weeks apart, followed by an approximate six-month break.



Second-Line Agents

If **first-line agents** such as those listed previously do not control NMO, the clinical team may suggest different agents that may have more benefits in some patients. These so-called **second line** medications may be used along with other treatments previously listed. Each medication suppresses the immune system in a powerful way – and as with all such medicines – **the effects can come with unwanted side effects too.**

Cyclophosphamide (Cytoxan®): this drug is another well-established agent that is known to generally suppress the immune system. When activated by the liver, cyclophosphamide calms the immune system by preventing the production of new immune system cells.

While there are many known side effects of this drug, there is little evidence for its use in NMO.

Methotrexate (Rheumatrex®, Trexall®):

Methotrexate inhibits the production of a vitamin-like factor called **folic acid**. Because they reproduce quickly, cells of the immune system require high levels of folic acid for normal growth. For this reason, methotrexate is used to calm the immune system by inhibiting new immune system cells. This drug is non-specific, and **can lead to increases in infection**. In high doses, methotrexate is used to treat cancer.

Mitoxantrone (Novantrone®): originally developed as an anti-cancer agent, mitoxantrone inhibits many types of immune system cells, including T and B cells, as well as other white blood cells called **macrophages** and **neutrophils**. This treatment reduces the activity of the immune system, thereby reducing inflammation. It is also commonly used in multiple sclerosis (MS) and cancer treatment.



Important Reminder: All treatments that reduce the activity of the immune system have side effects, many of which can be serious or even life-threatening. Patients are at a higher risk for some infections that the body would normally combat. If you and your clinical team choose to use such agents, **careful monitoring of the immune system is important to address these potential risks**. For example, blood tests for **a full blood count** and **white blood cell count** are often checked routinely, and **kidney or liver function testing may also be required**. Some patients require preventive vaccines against pneumonia, influenza, or other infections before using immune suppressing drugs, and may also be prescribed preventive low doses of antibiotics for a long period of time. In any case, it is critical to ask your doctor what may be the best treatment and preventive plans in your particular case.

Careful monitoring of the
immune system is important to
address potential risks.

Also, if you develop any side effects, fevers or signs of infection, it is important to contact your medical care team immediately.

3.3 Recovering from a Relapse



QUICK READ

Recurrent episodes of NMO attacks are called **relapses**. It is not known what causes relapses in NMO, and they can come on suddenly and without warning. Relapses and recovery times vary from person to person. Likewise, recovery can depend on many factors, including the severity and duration of the attack. Some symptoms can be long-lasting, while others resolve partially or completely.

Regaining function after a relapse can vary greatly from person to person. After symptoms are evident, conditions may worsen over hours or days. **Because rapid treatment is crucial, it is important to notify your physician immediately if you sense a relapse.** Eventually, with appropriate treatment over time, many patients may regain some if not all function in the affected areas. **Monitoring symptoms and staying in close communication with your team of clinicians is essential for treating relapses and improving the outcomes of recovery from a relapse.**

Managing Symptoms of NMO

NMO is a disease that can have very different symptoms in each patient. Many symptoms may improve over time, **especially if treatment is received early.** However, the effects of relapses may be cumulative, and each

If nerve fibers have been permanently damaged, long-lasting changes in strength, balance, vision, bowel or bladder, or other functions may result.

attack may lead to additional damage in the nervous system. If nerve fibers have been permanently damaged, long-lasting changes in **strength, balance, vision, bowel or bladder, or other functions may result.** The following text lists a few of the more common symptoms that NMO patients may experience:

- **Neuropathic (nerve) pain** in NMO results from injured or damaged nerve fibers. Nerve pain can vary quite a bit from person to person. For example, **some patients experience numbness in affected areas.** For others, the pain is described as a **burning sensation.** It can have a **“sharpness”** or a **brief “shooting” quality,** as well as **tingling, crawling,** and/or **“electrical” sensations.** Many different medications that may effectively control neuropathic pain may be considered by your clinical team.
- **Changes in muscle tone** can occur in NMO when communication between the brain and spinal

cord is affected. Without normal transmission of signals from the brain or spinal cord, nerves can send incorrect signals to muscles to relax or contract in an uncontrolled manner. Generally, there are two types of effects that may be experienced:

- Increased muscle tone or **spasm.** Spasms occur when there is too much nerve stimulation to muscle, causing excessive contraction
- Decreased muscle tone or **weakness.** Muscle weakness occurs when there is too little nerve signal to muscle. Increased or decreased muscle tone can reduce strength or endurance, and may be accompanied by pain or cramping. An exercise or stretching plan designed with your clinical team may help improve muscle tone.





- **Joint stiffness** is a symptom often caused by changes in muscle tone and/or inflammation. The result is reduced mobility of a joint, such as a knee, elbow, or shoulder. Often times, joint stiffness may be worse early in the morning or late in the evening. **Exercise** or **stretching** can help manage stiffness and pain. Sometimes **medication** or **external treatments** (heat or cold application, or physical therapy) may be needed. Your physician or physical therapist can help determine the best way for you to manage or treat joint stiffness.
- **Bladder symptoms** can occur in NMO, and may include **urgency**, **frequency**, **hesitancy**, or **difficulty initiating urination**. Other symptoms such as **nocturia** (awakening at night because of the need to urinate) and **retention** (unable to pass

urine) may occur due to spinal cord injury. In some severe cases, catheterization may be required to relieve urinary retention. For conditions of urinary incontinence, medicines may be prescribed by your doctor.

- **Bowel symptoms** may also occur in NMO, and can include constipation and loss of bowel control. Urgency may also be experienced, due to changes in spinal cord and nerve function. **If recommended by your clinical team, a high-fiber diet, fluids, laxatives, stool softeners, and abdominal massage may help manage symptoms.**
- **Sexual dysfunction** in NMO may result from changes in nerve function, resulting in a lack of sensation or numbness. Men may experience difficulty in achieving erection, and women or men may have difficulty reaching orgasm. Managing symptoms often varies from person to person. Medications or alternative therapies such as **biofeedback therapy may be helpful if indicated and prescribed by your clinical team.**
- **Osteoporosis (brittle bones)** may result from long-term use of steroid medication or lack of weight-bearing activities. If practical, **an exercise plan approved by your physician can be a natural way to strengthen bones.** Adding **vitamin D** or **calcium supplements** to your diet may also be important considerations to discuss with your doctor.



- **Depression** can be a natural and normal symptom associated with NMO and other chronic autoimmune diseases. Symptoms may occur for many reasons, such as **changes in quality of lifestyle**, **loss of vision** or **sensation**, or **stress** within personal relationships. Treatment for depression often consists of **counseling**, **medication**, or both. It is important to discuss your feelings with your clinical team to consider the best ways to manage any emotional impact of NMO.
- **Visual symptoms** in NMO may include **eye pain** that is worsened by eye movement, **vision loss** over hours or days, changes in the field of view (such as loss of **peripheral vision**) or perception of colors and depth. Such symptoms most commonly result from inflammation in the optic nerve (**optic neuritis**) that connect the **retina** of the eyes to the brain. With appropriate treatment, many NMO patients

experience improved visual symptoms following a first attack or relapse, especially when treatment is started early.

Managing Permanent Disability

Creating a Holistic Care Plan

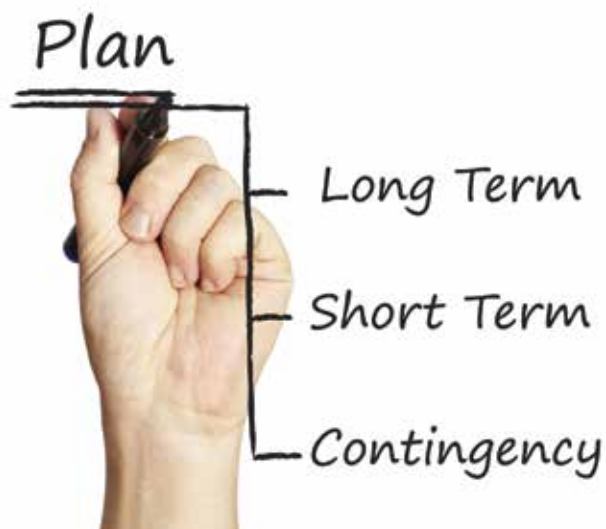
Symptoms experienced in NMO can persist over long periods of time, overlap with other symptoms, or have indirect effects on other day-to-day functions. For example, pain interferes with activities such as housework, employment or exercise. In turn, these effects can have negative impacts on self-esteem, mood, sleep, and personal or professional relationships. Although each problem may be tackled individually, many NMO patients find it helpful to address their overall health through a multi-disciplinary approach, including **holistic** care.

In an effective holistic care plan, good communication occurs among doctors, nurses, and a team of health specialists including:

- Alternative
- Psychological
- Social
- Spiritual health experts
- Physical therapy

Importantly, this team creates a coordinated plan to manage the unique healthcare process of each NMO

patient. In addition to continuing evaluations and treatment as appropriate, vision or mobility aids (e.g. **walkers** or customized **wheelchairs**), home health care (e.g. **visits by healthcare professionals to your home**), or **custom home remodeling** can be part of a multidisciplinary management plan and may improve quality of life.



Can long-term symptoms improve significantly?

It is always possible that long-term symptoms may improve or resolve over time. However, based on current knowledge it is rare for symptoms that have existed for years to resolve significantly or entirely. Residence adaptations (e.g. home modifications), mobility aids (e.g. walking aids or wheelchairs), and lifestyle modifications (e.g. change of job, move to a single-story house) may best be planned in advance. This

As in many autoimmune diseases, NMO can cause a broad spectrum of symptoms that may vary widely, with every patient affected differently.

way, time and resources can be focused on improving quality of life, rather than waiting for “miracles to happen” or trying unproven or potentially dangerous approaches, which can be very costly. Consulting with your clinical team – including a qualified occupational therapist – as early as possible can be important to help guide your planning, and may be covered by medical insurance. Please see Section 4, *Living with NMO*.

How severe can NMO be?

As in many autoimmune diseases, NMO can cause a broad spectrum of symptoms that may vary widely, with every patient affected differently. Disease symptoms can range from mild – such as a single relatively benign attack of optic neuritis with a near-complete recovery and no further relapses – to severe symptoms and lasting effects such as blindness and/or paralysis. Although the factors that predict severity of disease are not yet known, there is a great deal of active research to help find these answers. Some of the more **severe** effects may include

loss of vision in one or both eyes, a degree of paralysis in limbs due to damage of the spinal cord, breathing difficulties due to spinal cord or other neurological issues, and even premature death.

However, with early diagnosis and effective treatment, many of these consequences can be managed effectively, allowing people to reduce the impact of NMO on their daily lives.



What about Alternative Therapies?

Alternative and complementary therapies can be used to target a specific physical, mental, emotional or spiritual problem. They can also be used as preventative measures or purely for relaxation, and may increase

your feeling of well-being. Although this guide makes no recommendations for clinical care, reflexology, massage, Reiki or acupuncture, these may help to keep sleep patterns, relieve pain or reduce stress and tension. **Consult your physician and care team for more information or specific recommendations.**

There is little research to show how effective any of these treatments may be. Therefore, **it is generally recommended that they not replace the pharmacological treatments** that your neurologist, general practitioner (GP), or other healthcare professional/s prescribe, but they may **complement their effect by being added into your care plan when appropriate.**

The **reduction in stress** has been shown in scientific literature to help stabilize some autoimmune diseases, especially when part of a medical treatment plan.

Alternative and complementary therapies can be used to target a specific physical, mental, emotional or spiritual problem.



3.4 Pregnancy and Pediatrics

NMO and Pregnancy

The hormonal changes during pregnancy modulate disease course in several autoimmune conditions such as multiple sclerosis (MS), systemic lupus erythematosus, and Sjögren's disease. Similarly, **relapse rate is influenced by pregnancy in neuromyelitis optica (NMO)**. Like MS, several studies from different geographic populations suggest NMO relapses increase in the months immediately following childbirth. In addition, there is a **high likelihood** of initial NMO symptoms and diagnosis during the **post-partum period**. There are studies with some indication that **relapses may increase during pregnancy** as well, signifying that pregnancy may not confer the same protective properties to disease course in NMO as with

MS. Because of the potential severity of relapses and the unique considerations of pregnancy, your clinician may advocate continuing treatment or changing to a different treatment during pregnancy. **This is an important discussion to initiate with your clinician early on in the process of considering pregnancy so that a plan can be formulated ahead of time.**

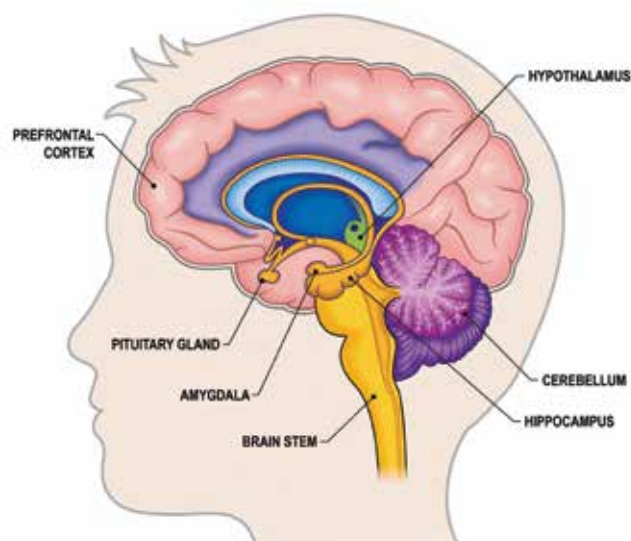
Currently, there is no consensus on what are the most appropriate treatment options during pregnancy. However, there is greater acceptance for the need to treat aggressively during the post-partum period because of the higher risk of relapse. Larger studies are needed to determine if the incidence of pregnancy related complications and infertility differ in NMO from the general population.



NMO in Children

The **pituitary** is the master gland located in the middle of the head, just below the brain and behind the eyes.

The pituitary gland **regulates the thyroid gland, adrenal glands, ovaries and testes.** The pituitary also helps regulate the amount of salt and water in blood. **Growth Hormone from the pituitary enables children to grow taller.**



The pituitary gland is controlled by a small brain region called the **hypothalamus**. The hypothalamus connects to the pituitary by a thin stalk of vessels that **allows direct communication from the hypothalamus to the pituitary**. The hypothalamus is **rich in Aquaporin-4** so an **NMO attack on the hypothalamus can disrupt pituitary function**.

Who gets pediatric NMO?

Current studies suggest that approximately three percent of all NMO patients experience their first symptoms

in childhood or adolescence. **Patients as young as 16 months have been reported with NMO.** The average age for children is 10 years old. Both boys and girls can be affected, but like in adults, there is a female bias at approximately 2:1.

Symptoms of Pediatric NMO

Children with NMO usually present with “attacks” of new neurological symptoms appearing within a **few hours or days**. Children with NMO can have attacks with symptoms of blurred vision, or loss of vision in one eye or both eyes. Some children experience other possible symptoms including:

- Weakness or numbness (tingling / itching) of the arms or legs
 - Confusion or extreme lethargy at their attacks
 - Stomach pain, nausea, vomiting, hiccups
 - Fever or seizures
 - Muscle spasms / backaches
 - Headaches
- » **Some children with pediatric NMO may be shorter**, maybe because of prolonged steroid use or maybe because of abnormal pituitary function.
- » Some children may have **abnormal sodium levels** in their blood during an attack.

» **Puberty may come early or be delayed** in pediatric NMO patients. Some girls with previously regular menstrual cycles will develop irregular periods. Even with these problems during puberty, males with NMO can father children and females with NMO can become pregnant and have healthy babies with proper medical care.

Keeping relapses at bay may be most helpful in managing these symptoms.

The effects of relapses in NMO patients tend to be greater than those in MS patients, including impacts on blood pressure, heart rate, and other functions of the body.

Diagnosis of Pediatric NMO

Diagnosis is usually made by a combination of **clinical features, appearance of lesions or “spots” on MRI**. Approximately **two-thirds of children** with NMO can also have an **antibody to aquaporin-4** in their blood or spinal fluid, however this **antibody may not be present at the onset of the disease**, and may appear up to **two to three years later**. Pediatric NMO differs from MS in the **distribution of MRI lesions**, as well as the presence of the **aquaporin-4 antibody**.

Treatment of Pediatric NMO

Although there are **no FDA approved treatments**

for adults or children with NMO, children are usually offered **immunomodulatory treatments**. Attacks are treated with a short course (usually up to a week) of **intravenous steroids**, or **IVIG or plasmapheresis**. It is important to prevent new attacks in children with established NMO, and treatment with mycophenolate mofetil, azathioprine or rituximab is usually offered.

Research in Pediatric NMO

There is ongoing research to understand the causes of pediatric NMO including genetic associations. As well, studies of better diagnostic and imaging criteria are underway to improve recognition of this condition.

Treatment studies and clinical trials of new treatments include children when appropriate.

Management and Support for Pediatric NMO

There are several centers across the U.S. and the world that have experience in treatment children and adolescents with NMO. Care includes neurological

Diagnosis is usually made by a
combination of clinical features,
appearance of lesions or “spots” on MRI.

expertise, family support, therapists and affiliation with an educational specialist. Care is often co-managed by a specialist team as well as a patient's local neurologist or pediatrician.

3.5 Creating a Healthcare Team



QUICK READ

Healthcare professionals working together as a team may offer the most effective way to manage NMO. Start with the list below when considering a healthcare team:

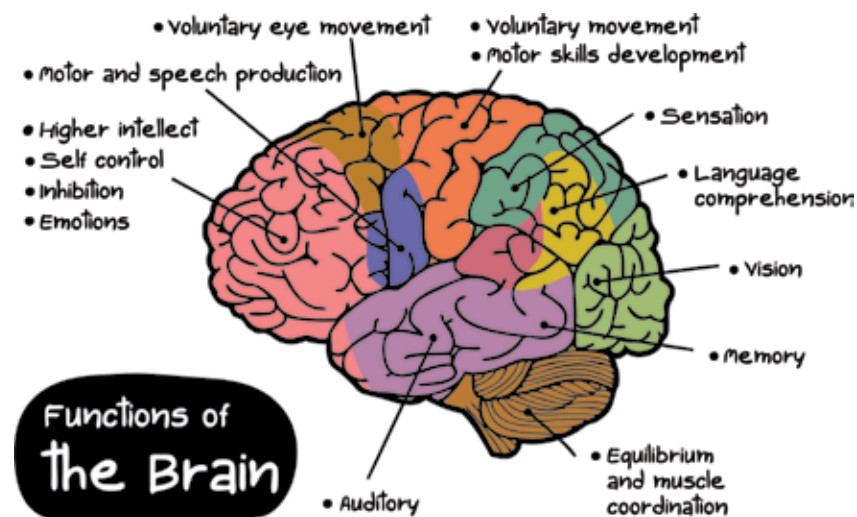
- Primary Care Physician
- Neurologist (central nervous system specialist)
- NMO Specialist
- Pediatrician
- NMO Nurse Specialist
- Ophthalmologist (eye doctor)
- NMO Clinical Fellow
- Physical Therapist
- Occupational Therapist
- Psychologist
- Dietician

NMO is a complex disease, and many patients benefit from a team of different healthcare professionals to help manage their health. This section aims to define their different roles.

General Practitioner (GP) / Primary Care Physician (PCP) / Primary Medical Doctor (PMD)

The primary physician is responsible for providing comprehensive healthcare to every individual seeking medical care. With his or her team, this doctor arranges day-to-day care, such as prescribing medications and monitoring blood results, with the advice of the subspecialty neurologist.

The NMO specialist works closely with the primary physician (and team) to ensure that all aspects of care are monitored and updated as necessary.



Local Neurologist

A subspecialist neurologist uses his or her expertise and knowledge to diagnose symptoms and may refer a patient

to other specialists, such as a neuro-ophthalmologist, for further advice on diagnosis and management.

The neurologist will be closely involved in the care of the patient alongside the team of providers. The neurologist may be seen for regular follow-ups or perhaps if needed, to admit the patient to a hospital at the time of a relapse.



NMO Specialist Neurologist or NMO Subspecialist

This neurologist knows all general neurology but has been trained and has specific experience and expertise in the arena of NMO. The NMO specialist neurologist ensures the correct diagnosis is made and determines the most appropriate treatment for patients with a diagnosis or suspected diagnosis of NMO.

He or she is responsible for leading and managing care and works closely with the specialist nurses and other members of the NMO team to ensure the best possible care is delivered.



General Pediatrician

For children and adolescents with NMO (generally under age 18), all care is managed by their pediatricians and/or pediatric neurologists who work closely with the NMO clinical team. In a similar way to the NMO specialist neurologist, the pediatrician will work closely with local doctors and therapists to ensure continuity of care for patients. It is important to have a pediatrician closely involved in the daily management of all pediatric cases of NMO since drug dosing and side effects can vary more so in children than adults.

NMO Nurse Specialist

Some, but not all medical neurology groups have an NMO nurse specialist, who is the first point of contact for any concerns about NMO. The NMO nurse specialist will take time to discuss the patient's diagnosis, specific problems that the patient may encounter and answer any questions the patient may have. The NMO nurse specialist can provide:

- Information on the **condition, symptoms, medications** and **therapies** available to increase understanding.
- Information concerning **new symptoms** or **worsening** of existing symptoms.
- **Support** with **relapse issues and concerns**.
- **Facilitation** for working effectively with **healthcare professionals** such as neurologists, physicians and occupational therapists as well as nutritionists and other medical professionals.
- **Education for other healthcare professionals** who come into contact with NMO patients.
- Act as the **conduit** to get **clinical information** to the primary doctor, pediatrician, and/or neurologist/ NMO team.

Consultant Ophthalmologist

The consultant ophthalmologist is an **expert in the assessment of visual problems** such as optic neuritis (ON). The consultant ophthalmologist may also arrange scans and other tests to assess vision. He or she discusses findings with the NMO neurologist and connects patients with persistent visual problems to appropriate local support services for visually impaired people.

Neuro-Ophthalmologist

A neuro-ophthalmologist is a medical doctor trained in either neurology or ophthalmology who then subspecializes in the other field. Thus, this physician has an **expertise in both neurology and ophthalmology** and generally practices and studies central nervous system (CNS) diseases that affect vision.

Some patients see a neurologist who is a neuro-ophthalmologist who manages all aspects of NMO. In other cases, a neurologist may refer patients for consultation with a neuro-ophthalmologist for help with diagnosis, treatment and clinical follow-up related to their vision.

A patient is encouraged to take an active role to help maximize independence and function.



NMO Clinical Fellow

An NMO Clinical Fellow is a **licensed neurologist, M.D.**, who is **gaining experience** in a specific area (in NMO's case, neurology). Clinical Fellows have interest in clinical care and often conduct research. A patient may meet a Clinical Fellow during a visit to the NMO clinic or while being admitted to the hospital for care.

Physiotherapist (PT) or Physical Therapist (PT)

Physiotherapists **identify and maximize body movement**. A physiotherapist will assess physical problems such as poor balance, limb weakness, stiffness and spasms. They will advise on current levels of activity/exercise/physical care programs, prevention, treatment and rehabilitation.

A patient is encouraged to take an active role to help maximize independence and function.
Referral to local services for further input or provision

of aids such as walking sticks, hand supports and wheelchairs can be made. PTs are covered by most general insurance plans.



Occupational Therapist (OT)

The role of the occupational therapist is to **maintain the patient's independence**. This includes addressing activities related to personal care, domestic tasks, hobbies and employment that may be increasing in difficulty due to fatigue or loss of function. Occupational therapists work to find different ways of doing things to maintain independence and well-being. OTs are usually covered by most general insurance plans.

Clinical Psychologist (CP)

Clinical psychologists **support people with the**

emotional adjustment of managing NMO. By looking at emotional problems in the context of the whole of the patient's life, psychologists can suggest coping strategies. They can also access cognitive problems (memory, thinking, focus) and make recommendations. **Psychologists are different from psychiatrists in that they don't medically diagnose mental health problems or prescribe medication.**

The Dietitian

The role of the dietitian is to **provide advice on nutrition, health and food related problems**. For people with NMO, advice may be given for weight management (weight gain or loss) or optimizing nutritional status, and for customizing special diets that may reduce bowel inflammation (e.g., acids, glutens, caffeine, alcohol), help manage weight issues and all nutritional concerns.

Continence Advisor

NMO patients may experience symptoms related to bowel and bladder function. Bladder and bowel problems can restrict daily activities and lead to embarrassment and isolation, affecting both physical and mental health. Continence advisors **assess bladder and bowel problems, review medication regimens, suggest exercises to improve urinary and fecal incontinence and provide advice regarding healthy living (diet and fluids).**

Pain Management Team

Suffering from chronic pain can prevent living normally and having meaningful relationships with others. Pain management teams often **include physicians, nurses, physiotherapists, occupational therapists and psychologists and function in an “interdisciplinary” way.** This approach ensures better pain management and coordination of care so that treatment goals are met.

3.6 Managing Diet and Nutrition



QUICK READ

Many medical caregivers and patients view dietary strategies as an important component of their treatment plans as a means to control or slow down NMO's effects on the body, and help maintain overall good health.

Many people with NMO and related conditions would like to use dietary approaches to try to control the disease. The goal is to slow down the disease process in a safe and natural way. Paying close attention to diet and nutrition may provide a sense of control, hope and empowerment. **Medical caregivers generally agree that healthy diets are an important part of the overall care plan for their NMO patients.**

For those interested in using dietary strategies for NMO, it is extremely important to be well informed. High quality information allows one to identify and use approaches that are low risk and potentially beneficial, and avoid those that are possibly harmful or ineffective. Due to the complexity of NMO and NMO medications, it may be difficult to obtain high quality, unbiased NMO-specific dietary information. **Some people who provide dietary information may have financial incentives, biases, or limitations in their knowledge base that lead them to provide inaccurate and sometimes potentially dangerous information.**



To help people with NMO make informed decisions about diets and dietary supplements, refer to the article “Diet and NMO: A Three Step Approach” on the GJCF website at:

www.guthyjacksonfoundation.org/pdf/Diet_NMO.pdf.

The aim of the article is to highlight the following points:

- Before trying specific dietary approaches (or any other unconventional therapies), the risks and benefits of these approaches should be discussed with your health provider.

- There are multiple conventional medications that have been studied and shown to have beneficial effects on the disease process of NMO.
- Unfortunately, no dietary approach has ever been systematically studied in NMO. For those who are only interested in absolutely proven therapies, there is not a dietary approach that can be formally recommended as of yet.

The article provides information about approaches that are not absolutely proven but are low risk and may possibly benefit the underlying disease process in NMO.

It’s a given that you must talk with your doctor about dietary strategies as a component of your treatment plan. Some clinics have an on-site nutritionist while others have a recommended reading list for those interested in monitoring their nutrition as an attempt to control symptoms of NMO.

Do you know?

NMO clinical trials are essential to advance the understanding of NMO. Read more about clinical trials in Section 5.1.

Living with NMO



Living with NMO

- 4.1 Fitness
- 4.2 Managing Fatigue
- 4.3 Coping with Loss of Vision
- 4.4 Managing Bowel and Bladder Problems
- 4.5 Occupational Therapy
- 4.6 Support with Daily Life
- 4.7 Daily Living Equipment
- 4.8 Modifying Your Home
- 4.9 Driving and Transportation
- 4.10 Social Security Disability Benefits in the U.S.
- 4.11 Support for Caregivers

4.1 Fitness

QUICK READ

Exercise routines vary from person to person depending on overall health, degree of symptoms, limitations and fitness levels. Healthy lifestyles contribute to healthy immune systems. Seek a doctor's or physical therapist's advice before beginning any exercise program.



A **healthy lifestyle** encourages a strong immune system, defending the body against attacks. This means getting regular exercise and enough rest. The benefits of exercise include:

- Improved muscle tone and flexibility
- Increased mobility and endurance
- Better bladder and bowel function
- Reduced fatigue and depression
- Improved attitude and desire to participate in social activities

The type of exercise that works best for you depends on your symptoms, fitness level and overall health. Ask your doctor's advice before beginning any exercise routine for recommendations about:

- **Appropriate exercise programs** vs. those that should be avoided.
- **Intensity of the workout** (how hard you should be working).
- **Duration of workout** and any physical limitations.
- **Referrals to other professionals**, such as a physical therapist, who can help create a personal exercise program that meets your needs.
- **Avoid becoming overheated.** NMO pain symptoms may be more pronounced if the body is overheated. You will find a number of personal cooling devices on the market today. Your doctor may have recommendations for cooling measures and devices to best meet your needs.

Yoga has been reported as a good choice of exercise to help people with NMO.

Yoga has been reported as a good choice of exercise to help people with NMO. Yoga emphasizes relaxation, breathing, stretching and deliberate movements, with physical benefits including flexibility, strength, muscle tone, pain prevention and better

breathing. Improvements in mood and well-being, better sleep and increased energy have also been reported.

It's easy to become overwhelmed by the many different types and varieties of yoga programs. Although they may differ in their philosophy and postures, fundamentally all yoga styles have a number of qualities in common including:

- **Breathing techniques** to focus the mind on the body.
- Individualized, non-competitive and **adaptable programs**.
- Emphasis in **alignment**, which benefits posture and balance.
- **Muscle strengthening** and stretching education.
- **Tension release** allowing the body to feel more energized.
- **Relaxation techniques** to reduce stress.

Although they may differ in
their philosophy and postures,
fundamentally all yoga styles have a
number of qualities in common.



- **Locating a yoga class close to home will help you to attend regularly. If a stretch or pose doesn't feel right, listen to your body. Talk to your instructor after class**

People with NMO are able to exercise in many different ways. Because no two people experience NMO in the same way, exercise programs should account for **individual capabilities and limitations**. The advice of a physical therapist or exercise specialist can help to identify goals and target programs that are safe and beneficial for the maximum potential of muscle, bone and respiration. If changes in mobility occur, ask your specialist to recommend modifications.

Keeping a regular exercise routine is an important lifestyle strategy for managing complications and maintaining physical and mental strength for people with NMO.

4.2 Managing Fatigue



QUICK READ

To help manage fatigue, pace yourself as you perform daily activities. Meal planning, electronic equipment, and setting a daily schedule can help to accomplish your daily goals. Accepting help from family and friends benefits everyone.

Varying degrees in symptoms of fatigue are common among those with a neurological condition. Some patients report no fatigue while others report experiencing extreme fatigue.

What is fatigue?

Fatigue is generally defined as a feeling of **lack of energy and motivation** that can be physical, mental or both. The sensation of fatigue is associated with feeling **tired, weary, exhausted and weak**. Try not to get discouraged. Nearly everyone struggles with being overtired or overworked from time to time.

Fatigue in NMO

Some people with NMO experience overwhelming exhaustion by simply carrying out their everyday activities. Without warning, accomplishing routine tasks may become a massive challenge. This level of tiredness can be difficult to understand and easily lead to frustration and feelings of guilt or inadequacy.

What causes fatigue?

It is difficult to determine a specific reason for fatigue, which is commonly found in people with neurological conditions. Possible causes include:

- **An initial attack or relapse** that requires the body to compensate during recovery for the changes that have occurred. Over time, fatigue may improve or disappear completely.
- **Getting used to a new way of life.** Living with NMO is not easy and is physically and psychologically tiring.
- **Sleep disturbances** perhaps due to pain or

continence issues. After a period of time, a patient may feel the effects of sleep deprivation and exhaustion.

- **Low mood, depression, frustration and anger** which are feelings that can be associated with changes in life.
- **Medications** that can lead to feelings of tiredness and lethargy.

After a period of time, many people with NMO are able to determine which activities or events are likely to cause, increase, or decrease the chances of fatigue. While some report that physical activity increases their level of fatigue, others report a benefit from being active. Sometimes fatigue is caused by setting unrealistic goals and trying to accomplish too much too soon. Remember to pace yourself.

After a period of time, many people with NMO are able to determine which activities or events are likely to cause, increase, or decrease the chances of fatigue.

What is it like to live with fatigue?

Fatigue is subjective, hard to explain and difficult to measure. It can be difficult for others to appreciate and understand how debilitated a person may feel, even though they may appear fine. **Employers, friends and loved ones may all struggle to understand and empathize with fatigue, resulting in additional anxiety and stress for the person living with NMO.**

The Spoon Theory

One aspect of fatigue that others often don't understand is the way that fatigue can limit what you can do.

In a blog called "The Spoon Theory" Christine Miserandino, a speaker, journalist, blogger and patient advocate from New York describes her experience of living with fatigue in the hope that others will better understand.



“Christine and her friend were in a restaurant when her friend asked Christine what it was really like to live with a long-term health condition.

“Christine grabbed a handful of spoons and handed them to her friend. The spoons each represent one task or one thing that uses up energy. The point is that for people with a disability, there is only a limited number of spoons available to use in one day and in some days you will have more spoons than on other days, for example after a bad night’s sleep.

“With just one spoon left at the end of the day, Christine explained to her friend that if she cooked, she wouldn’t have enough energy to wash up. If she went out for dinner she may be too tired to drive home safely. She has learned to plan her day and always keep a spoon in reserve in case it is needed.”

Many people identify with this story. Does it sound familiar?

The theory is available in full on her blog:
www.butyoudontlooksick.com.

Ideas for managing fatigue

Implementing the following suggestions may minimize the effects of fatigue:

- **Plan:** Planning your daily, weekly or even monthly routine can help you prioritize your goals and prevent all the “little things” from piling up.

One key to being able to accomplish critical daily activities is to rest before your energy level is depleted.

- **Rest:** Don’t be afraid to rest more often than you feel you should. One key to being able to accomplish critical daily activities is to rest before your energy level is depleted. If you can, take several rest breaks throughout the day.
- **Sleep:** Make sure you get a good night’s sleep. If pain or incontinence issues result in disrupted sleep, seek advice from your doctor. Keep caffeine intake at a healthy level and arrange for support in caring for children during the nighttime. Try not to get upset if you can’t sleep. It may help to have a warm milk-based drink and listen to some relaxing music.
- **Daily Activities:** Prioritize your most important daily activities and don’t be afraid to tell others your schedule. Talking with others about what you need to do can sometimes help you prioritize your goals better as you “talk them out.” You never know, if you communicate more with others help may come when you least expect it.
- **Cleaning:** Letting go of the responsibility of caring for your home can be difficult. In an effort to save

energy, consider using lightweight equipment and carefully timing larger cleaning efforts. You may find a great benefit from accepting help with household chores or seek the help of a professional house cleaning service.

- **Laundry:** Try doing laundry one small load at a time throughout the week. This may help prevent doing multiple loads in one day, which can be exhausting.
- **Meal Preparation:** A good meal is a source of energy, health and togetherness. Menu planning saves time, simplifies life and makes meal time more enjoyable.



Plan ahead: A weekly meal plan can help to feel more organized and in control. Select easy recipes that don't require a lot of prep work. Make weekly grocery lists from the meal plan to avoid multiple trips to the grocery store. Accept help from family or neighbors. A well-written grocery list can be easily followed by a caregiver.

Shopping: Consider food shopping online and using home delivery services. Purchasing and storing precut, washed vegetables, fruits and frozen or canned foods may cost more but save steps in the end. Also, keep a good stock of "basics" which can be turned into simple, nutritious meals.

Preparation: Measure ingredients and arrange in the order they will be used to allow for interruptions. Use timers and reminder notes as needed. Make more than you need to use on days when you don't feel like cooking or have time. Consider using a slow cooker to enable having hot meals ready at the end of the day when you are feeling most tired.

Pace yourself: Divide food preparation throughout the day. Soak dishes and pans in the sink overnight, and complete cleanup in the morning when you have more energy.

- **Work:** In your workday, closely consider your roles, responsibilities and activities. Frequent breaks may prove helpful in your work schedule and help to manage your energy reserves. Take into account the

effect of your travel time to and from work. **You may want to use this NMO guide to help your employer and colleagues better understand the effects of NMO.**



- **Electric appliances:** Small, simple kitchen appliances can save energy but not if they are too complicated to dismantle and clean.
- **Wire mesh pan baskets:** When boiling vegetables or other foods, consider placing wire mesh baskets

in your cooking pans. They are easily lifted out for serving, removing the immediate need for heavy draining of pans full of hot water.

- **Mobility:** Each person's ability to walk and level of mobility is different. Some people with NMO will have little-to-no restrictions, while others will use walking aids or a wheelchair. It's important to remain as active and mobile as possible. Combining different forms of transportation, walking and using a wheelchair can help to reserve energy.

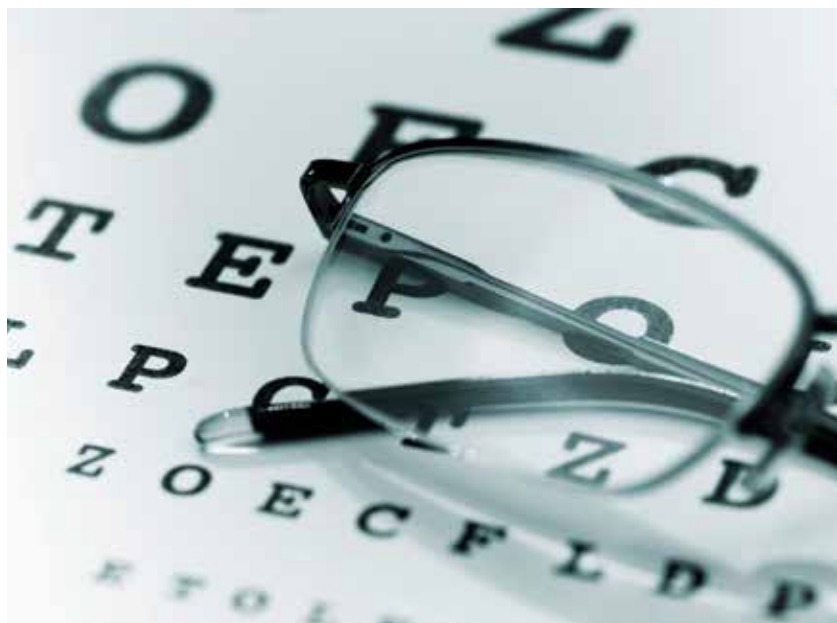


- **Leisure Activities:** It is widely recognized that a person's interests, hobbies and leisure pursuits provide an important meaning, balance and purpose in life. At the end of the day, you may find there is not enough energy left to try new activities or enjoy beloved past times. Planning ahead and saving energy may often help to regain leisure interests.

Further sources of information on fatigue

The National Multiple Sclerosis Society (NMSS) website features comments and thoughts from people living with fatigue, anecdotes and advice.
www.nationalmssociety.org

4.3 Coping with Loss of Vision



QUICK READ

The use of visual enhancements and technology can help NMO patients maintain more independence.

Vision problems are common in people with NMO who have experienced inflammation of the optic nerve. The optic nerve is the cable transmitting electrical signals from the light sensitive inner layer at the back of the eye (called the retina) toward the vision area of the brain.

Sight loss takes many forms. Visual impairment is a deeply personal experience and no two cases are the same. Some people can't see in the dark; others are affected by bright sunlight. Some have a restricted field of vision and many experience a loss of contrast. Sight varies. Some days we see better than others.

How is visual impairment measured?

Partial sight can be hard to judge, with there being so many variables. If you cannot read normal newsprint while wearing glasses or contact lenses then you could be considered partially sighted. Blindness and partial sight are formally defined terms which relate to the quality of vision, but **blindness does not necessarily mean the absence of light.**

Sources of support and services

Coming to terms with having a sight problem can be tough. Dealing with the emotional and practical impact of changes to your sight can be overwhelming, especially if there has been a sudden and unexpected deterioration as can be the case in NMO.

It is important to remember that you are not alone and that information, support and services are available to help you live your life independently.

Everyday equipment to make life easier

A wide range of tools and gadgets are available to manage household tasks. A few examples are:

- Devices that alert you when a pot of liquid begins to boil
- Gadgets that make a sound when a cup you are pouring water into is nearly full
- Knives with an adjustable guide to help you cut even slices
- Tactile watches and alarm clocks

Accessible technology and telephones

Computer products and telephone systems that can be useful include:

- Mobile phones with tactile, well-spaced buttons and a function that reads text messages aloud
- Telephones with a large color contrasting keypad
- Computer screen reader
- Magnification software

4.4 Managing Bowel and Bladder Problems



QUICK READ

Bowel issues are not uncommon. Evaluate your diet, research a bowel plan with your clinician, look into bowel-specific products and carry back-up supplies when you travel.

Incontinence has a significant emotional and psychological impact on those who suffer from the symptoms. At the very least, incontinence is embarrassing and distressing. It has a tremendous impact on social and work situations, sexual intimacy and relationships.

It is not unusual for patients with NMO to have bladder issues. Sometimes the bladder is overactive. Other patients might have issues with urine retention to the point of overflow. If you are having bladder issues, your physician might request a urodynamics study. There are also self-help measures that can be used.



Sometimes diet can exacerbate bladder symptoms. Avoiding caffeine and acidic foods can aid bladder control. **Many patients keep a daily diary of fluid intake and output to accurately monitor their bladder habits.**

Bowel issues are also not uncommon. Not being able to initiate a bowel movement or lacking bowel control that contributes to accidents can be very troubling for NMO patients.

Avoiding caffeine and acidic foods can aid bladder control.

Many patients are introduced to a bowel plan by their physicians. **Setting aside a regular time each day to empty the bowels can greatly improve a patient's situation.** Some patients use combinations of daily stool softeners along with a diet that is rich in fiber. Some use digital stimulation (digi-stim) which causes relaxation of the anal sphincter and facilitates bowel emptying.

There are many products available that are used to avoid embarrassing bladder or bowel accidents. There are absorbent pads and adult pull-ups that cannot be seen under clothing. **Many patients carry emergency supplies with them that include disposable moisturized wipes, spare undergarments, antibacterial soft soaps and zip lock bags.**

NMO patients are strongly encouraged to discuss incontinence with their doctors who can provide a viable program for better management and referral advice as needed. With advice from physicians and diligent attention to bladder and bowel habits, most patients are able to carry out everyday routines without incontinence issues negatively impacting their lives.



4.5 Occupational Therapy

Occupational Therapists are health professionals who work with people who have a medical condition, a physical disability, a mental health difficulty or a learning disability. They help people who have difficulties with everyday tasks such as preparing a meal, taking a bath or lifting their legs into bed. The aim of occupational therapy is to enable you to live as independently as possible at home, at work, at school and during leisure time.

An Occupational Therapist can help you adapt to changes in your life and overcome practical problems by:

- Looking at ways an everyday task can be done differently to maintain your independence or reduce the effects of pain and fatigue

- Offering advice on daily living equipment that may help you to maintain your independence with a specific task or activity
- Recommending alterations or changes to your home to make it more accessible or safer for you
- Helping to address education or work issues

4.6 Support with Daily Life



QUICK READ

Balancing the many life roles people have can be tricky. Identifying daily essential activities can help NMO patients determine what they can accomplish independently and where they may need help.

Coping with difficulty in carrying out your daily activities may present a challenge. These difficulties can be experienced for a variety of reasons including fatigue, pain, and weakness due to the psychological impact of living with NMO.

Sometimes solutions are within your grasp by asking yourself, “Is there a way of doing this differently?”

Identify your most important roles and activities

It may be helpful for you to make a list of your activities in a 24-hour period. Begin with the moment you wake up in the morning until you go to sleep at night. Include any activities during the night if you awaken. Next to each activity record if you need help or note an “OK” if you need no assistance.

You will be astounded at just how complex our daily lives are in meeting our basic needs from washing and dressing to household chores, shopping, cooking, employment, leisure activities and socializing.

Why are roles important?

Our roles in life make us who we are; they define us. These roles are many and varied including employee, student, caregiver, homemaker, cook, shopper, cleaner, mother, father, daughter, son, volunteer, friend, lover, DIY expert and animal caregiver among others. If you have stopped being involved in one or more roles completely,

try to resume those things that have important meaning in your life. Where possible, find ways around the difficulties so you can continue to play an important part in the role.



What next?

From the list in the previous section, you could identify which activities are essential, which are desirable and which ones are not needed in your daily routine. This can help to focus energies on what is most important.

Our days, roles and routines are very different. Some of us may live alone while others have dependent children or care for an elderly relative. Our situations are unique and bring with them their own difficulties and also sources of support and solutions. **The lists you create can help provide you with a clear picture of which activities and roles are essential and desirable in your life.** These lists will also help to find solutions if possible.

Solutions

Remedies may be in the form of equipment, changing the timing of an activity, or receiving support from a family member, colleague or caregiver. For example, a solution may require you to use your left hand for activities rather than your preferred right hand. A wide range of products designed for left- and right-handed people are available as one possible solution. Questions regarding particular challenges in performing activities should be discussed with your doctor.

The National Multiple Sclerosis Society (NMSS) offers publications specific to self management, some of which are applicable to NMO patients. In addition, information on how to locate Self-Help groups across the country can be found at: www.nationalmssociety.org.

Create your own support group or join one of the many online NMO groups. Start by visiting NMOtion at: www.nmotion.guthyjacksonfoundation.org/advocate.

4.7 Daily Living Equipment

QUICK READ

Wheelchairs and scooters can help with mobility and help NMO patients gain independence.

The effects of NMO can sometimes make previously

simple, everyday tasks more difficult. **Equipment is available that can help to lessen these effects and help you to regain greater independence.**

This equipment is called **Daily Living Equipment**. It may be a small gadget such as an electric can opener that could help you with reduced grip. A stairlift is an example of a larger product; this may be chosen to overcome difficulties in climbing stairs due to weakness or pain.

Equipment can help with routine activities such as washing, dressing, cooking, getting out of bed, moving around and traveling, helping to retain independence at home, work and during leisure time.



Wheelchairs and Scooters

People with NMO can experience a decrease in mobility due to Transverse Myelitis (inflammation of the spinal cord – section 1.10). Many people experience a small

reduction in their strength perhaps requiring the use of a walking aid such as a stick or crutches while others may experience a greater loss resulting in inability or difficulty standing and walking.

For many this situation improves with treatment and rehabilitation to such a degree that use of a wheelchair is no longer needed. For some a wheelchair may be helpful at particular times to move more easily in certain places. A smaller number of people require the permanent use of a wheelchair.

People often find wheelchairs give them more freedom rather than less. Some people use a wheelchair for outdoor use only. Others use a wheelchair indoors, for example at times of increased fatigue or to create greater independence around their homes.

Types of Wheelchairs

There are hundreds of styles of wheelchairs for differing needs and abilities. They fall into three main categories:

- **Self Propelled** wheelchairs are often propelled by engaging the large side wheels. When required, most wheelchairs can also be pushed by an attendant (someone who helps push a wheelchair on someone else's behalf).
- **Attendant Propelled** wheelchairs are often pushed by an attendant and may not have large wheels to self propel.

- **Powered Wheelchairs/Scooters** run on batteries enabling the user to move easily and quickly without any physical effort. Designs vary for indoor and outdoor use. Batteries are charged overnight or when not in use.

All wheelchairs can be used in conjunction with an appropriate wheelchair pressure cushion for greater comfort, support and pressure relief (to help prevent skin damage/pressure sores due to prolonged sitting).

Wheelchairs are available in many different sizes and dimensions in order to provide correct levels of comfort and support. Some are able to tilt to create different seating angles and others increase in height to enable a user to reach something high up or communicate with others more easily at eye level.



4.8 Modifying Your Home

QUICK READ

Grab rails, shower chairs, and banisters installed in a home or apartment can be relatively quick fixes to help NMO patients gain mobile independence.

Some of the effects of NMO such as reduced mobility, pain or vision loss can result in difficulty getting around your home. **The layout of your home may provide you with full independence and ease of access.** Yet some people who are newly affected by NMO find that movement and access in their homes is limited, especially in areas including upstairs and outdoor areas.



A well-designed and accessible home can make a world of difference to your independence and ease of living.

Solutions vary. They may come in the form of a simple grab rail secured to the wall in your shower to help with stabilization, a second banister on the stairs in order for you to be able to hold onto either side, carefully positioned lighting to enhance eye sight, or more complex additions such as a stairlift or permanent ramp to your front door. A well-designed and accessible home can make a world of difference to your independence and ease of living. **There are hundreds of ideas and solutions available.** It is just a question of receiving the correct information and support for you.

Each person's home has a different ability for changes in lifestyle. Some homes cannot accommodate the necessary changes. It's possible that moving to a more suitable home may help some gain greater independence. However, time is often needed to come to terms with the changes needed.

4.9 Driving and Transportation



QUICK READ

A careful assessment by an NMO patient's team of doctors should be conducted to determine the level of driving capability. Areas to think about:

- Vision
- Physical ability
- Fatigue
- Climate
- Cognitive changes

Without question, driving is one of the most important areas of independence for many people. It is the one activity that enables connections

to work and socializing outside of the home. Driving is often a necessity and a convenience, and represents freedom. In contrast, the prospect of losing one's ability to drive triggers fears of becoming isolated, lonely and dependent. When NMO affects mobility, discussing the ability to drive can make a patient feel defensive and protective.

Many people with NMO can continue driving but within their limits. A careful assessment by the patient's team of doctors should be conducted to determine the level of ability to operate a moving vehicle. The demands of driving on the human body cannot be underestimated when determining whether one can continue to drive safely without taking chances that could affect the driver or others.

Vision: Assessing **visual acuity** (clearness of vision) is important to determine necessary adaptations that may be needed to fulfill driving regulations.

Physical/motor changes: For people with physical impairments, driving assessments include evaluation of motor involvement (muscle weakness), range-of-motion limitations, coordination and sensory deficits in arms and legs. Limitations in these areas can restrict the ability to operate a vehicle. **A wide range of adaptive controls may be considered for driving.** These controls generally require skilled professionals to assess, inform and install.

Fatigue: Planning ahead is key to preventing fatigue from impacting driving. Knowing and documenting when fatigue sets in and scheduling outings accordingly can go a long way toward managing the effects of fatigue on driving.



Heat: Heat **may cause symptoms to worsen**, so plan ahead by scheduling outings during the early part of the day and park in covered areas if possible. Also, consider remote car ignitions to enable starting a car. Cooling down a vehicle prior to driving can help reduce heat stress.

Cognitive Changes: Taking inventory of NMO symptoms as they relate to the ability to absorb, digest and sort out important information in order to make quick decisions is crucial to safe driving.

Regular checkups with your doctor will help to diagnose vision and motor changes. Together you can determine your ability to operate a motorized vehicle safely on public roads.

Public Transportation and Driving Services:

Many cities have vans with lifts that are specifically dedicated to patients with special mobility needs. These services vary from city to city. It is important to become familiar with your city's public transportation and car services to better plan your activities if needed.



4.10 Social Security Disability Benefits in the United States

Individuals who are unable to work due to neuromyelitis optica (NMO) may find it difficult to maintain a job and may face financial hardship. Without a source of income

or medical insurance, the financial toll may be significant. In certain cases, the **United States Social Security Disability** benefits may help alleviate the financial strain by offering a monthly payment and medical benefits to help cover the cost of medical care. **Understanding the Social Security Disability application process** is the first step toward receiving the financial help.

Understanding Social Security Disability Insurance and Supplemental Security Income

The **Social Security Administration (SSA)** operates two disability programs including **Social Security Disability Insurance (SSDI)** and **Supplemental Security Income (SSI)**. To qualify for either program you must meet the SSA's medical criteria, but you must also meet the financial program of the respective program that you are applying for as well.



Social Security Disability benefits may help alleviate the financial strain by offering a monthly payment and medical benefits to help cover the cost of medical care.

Generally, to **qualify for SSDI benefits** you must have earned enough work credits through previous work activity. In 2015, you receive one credit for each \$1,220 of earnings, up to the maximum of four credits per year. Each year the amount of earnings needed for credits slightly increases as average earnings levels increase. The credits you earn remain on your Social Security record even if you change jobs or have no earnings for a while. At age **62**, you need **40 work credits** to qualify for SSDI benefits, 20 of which must have been earned in the last 10 years. **Younger applicants may qualify with fewer credits.**

Unlike the SSDI program, the **SSI** program is not based on prior work activity. Instead, the SSI program is a **needs-based program**, where income and assets determine eligibility. As of 2015, your household income cannot exceed **\$733** per month as an individual or **\$1,100** as a couple to qualify. In addition, your household

While NMO is not included in the SSA's Blue Book, you may still be approved for Social Security Disability.

assets must also not exceed **\$2,000** as an individual or **\$3,000** as a couple.

Meeting the SSA's Medical Criteria

When you apply for Social Security Disability benefits the SSA compares your condition to a listing of conditions known as the Blue Book. This publication contains all of the conditions that could potentially qualify an individual for SSDI or SSI benefits, along with the criteria that must be met with each condition. **While NMO is not included in the SSA's Blue Book, you may still be approved for Social Security Disability benefits through what is known as a vocational medical allowance.** To achieve this, you must be able to prove to the SSA that your condition prevents you from performing any type of work activity whatsoever.

Preparing for the Social Security Disability Application Process

Since **NMO is not included in the SSA's Blue Book**, you need to take extra care when preparing for

the application process so that you can prove beyond a doubt that your disability completely prevents you from performing any type of work activity whatsoever. To do this, you should obtain copies of:

- Clinical histories
- Hospital records
- Lab results
- Treatment histories
- Written statements from treating physicians

By providing as much evidence as possible with your application, it will be easier for the SSA to understand how your condition qualifies you for benefits.



Applying for Social Security Disability Benefits

When you apply for disability benefits you will be asked to fill out a number of **forms**. Be sure to fill out each form in its entirety and provide as much **detail** as possible in your answers. You will receive a decision regarding your claim approximately **two to four months** from the date of your application. If you are awarded benefits, you will be notified as to what benefits you will receive, how much you will be receiving each month in the form of an SSDI and/or SSI payment, and when benefits will begin.

If you are denied benefits, you have **60 days** from the date of the notice to appeal the SSA's decision to deny your application.

Appealing a Denial of Benefits

If you must appeal a denial of benefits, you may want to consider retaining the services of a Social Security Disability attorney. These professionals can help you determine why your initial claim was denied and assist you in gathering the evidence needed to strengthen and support your claim. A disability attorney can also represent you before the administrative law judge at your disability hearing.

Sources

The United States Social Security Administration:

<http://www.ssa.gov/>

Social Security Disability Help:

<http://www.disability-benefits-help.org/>

4.11 Support for Caregivers



QUICK READ

Caregivers also need support to maintain a healthy and balanced life.

It's important to remember the needs of our caregivers.

Join or create an NMO Support Group.
See section 6.5 for more.

Caring for a relative, loved one or child with NMO can be a rewarding and fulfilling experience.

Caring for a relative, loved one or child with NMO can be a rewarding and fulfilling experience, but without the right support it may also be difficult at times. Some care providers live with the person they are supporting while others do not. Care providers are people of all ages, even children who provide care for a parent. **Care providers often have a need for information, financial and other support, and time away to connect with people who have similar needs.** It is perfectly normal to have complex feelings about the caregiver role. It may be challenging to cope with the life changes that occur when the role is assumed. **Support comes in many forms and may provide a tremendous help to a caregiver.**

Regular breaks from daily responsibilities are necessary to maintain good health, as well as eating well and exercising regularly. **It may be a good idea to accept help from a trusted friend or family member to allow time for the primary caregiver to run errands or visit friends.**

A caring role is not a conventional job. There is no need for a caregiver to feel guilty about wanting a break or needing time off. In the long term, time away will help avoid feeling isolated and depressed and improve coping with the demands of being a caregiver.



Become an NMO Advocate

Anyone can be an NMO Advocate,
and signing up is easy! See Section 6.2
to find out how.

Hope for the Future



**ANSWERS
AHEAD**

Hope for the Future

- 5.1 NMO Clinical Trials – Get Informed
- 5.2 What research is being done to support NMO?
- 5.3 Home Base Centers for NMO
- 5.4 Building a Biorepository
- 5.5 Donating to the Blood Bank - How does it work?
- 5.6 NMO International Clinical Consortium (ICC)
- 5.7 International Panel for NMO Diagnosis (IPND)

5.1 NMO Clinical Trials – Get Informed

What is clinical research?

Clinical research is medical research that involves **patients**. Patients, called **subjects** in clinical research, **volunteer** to participate in carefully designed and conducted **studies** seeking to **find better ways to prevent, diagnose, treat, and eventually cure human disease**. These advances come with improved understanding of the causes and effects of the disease. Clinical research includes **clinical trials** and **clinical studies** in which new treatments and strategies are tested in hopes of improving the health and wellness

of patients. In addition, clinical research can focus on **clinical science**, which assesses discovery aspects of medicine, including disease onset or relapse risks, genetics, epidemiology, and other features associated with cause or variable manifestations of disease. All clinical research is required to adhere to careful protection of subjects and their information, and clinical trials in particular are regulated and monitored by the **U.S. Food and Drug Administration (FDA)** and the **National Institutes of Health (NIH)**. For more information, please refer to the National Institutes of Health website: www.nih.gov

Why do we need clinical trials?

Clinical trials are designed to determine which medicines or procedures **best benefit patients**, and which may not. These studies often involve expert teams from **academic, governmental** and **pharmaceutical sectors**. In some cases, clinical trials seek to test the **efficacy of a new drug** for a disease which has no proven effective therapy. In other trials, one treatment is compared with another to examine which may be best in patients of differing disease stage or condition. Clinical trials are usually divided into different “**phases**”, each of which is designed to address a slightly different question:

Phase I: usually designed to test the “**safety**” and to learn the best dosing regimen of a new drug to minimize side effects. Subjects are usually healthy volunteers, and the study is often **relatively short** in duration. **Subjects do not usually benefit from a Phase I study.**

Clinical trials are designed to determine which medicines or procedures best benefit patients, and which may not.

Phase II: usually designed to study the drug based on **results from Phase I**. Here, the drug, device, or procedure is evaluated in volunteer subjects who have the disease of interest. Phase II trials further refine safety, minimize adverse events, and begin to **explore** if and how the test agent may benefit the subject. **Some volunteer subjects may benefit from a Phase II study.**

Phase III: usually **compares** the test candidate (drug, device, or procedure) to a commonly used agent that has been proven to be at least somewhat effective in treating a condition, if one exists. This phase is designed to understand if the test agent is better than existing approaches, and where the agent might best fit in managing a particular disease. For more information, please refer to the National Institutes of Health website: www.nih.gov



Why do people participate in clinical trials?

People participate in clinical trials for **many reasons**. Healthy individuals often say they participate to **help others** and to contribute to new or better ways to prevent or treat disease. **Volunteers who have a disease** also participate to help others, but **may also receive new or improved experimental treatments**. In addition, subjects who are involved in clinical trials receive **additional care** and attention from the clinical trial staff. Sometimes, blood relatives of the patients with diseases participate in certain trials which evaluate the genetic components that may pose potential disease risks. *Information courtesy of nih.gov*

Who participates in clinical trials?

People from all walks of life participate in clinical trials. Some are healthy, while others may have illnesses. Sometimes, blood or genetic relatives of a subject suffering for an illness can participate together in a clinical trial. Usually, each clinical trial or study specifies which subjects may participate. These terms are called the Inclusion Criteria or Exclusion Criteria. Factors that allow someone to participate in a clinical trial are “inclusion criteria.” Those that exclude or not allow participation are “exclusion criteria.” These criteria are based on factors such as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. Before joining a clinical trial, a participant must qualify for the study. Some research studies seek participants with illnesses or conditions to be studied in the clinical trial, others may need healthy volunteers whereas, some others, require both. *Information courtesy of nih.gov*

Subjects who are involved in clinical trials receive additional care and attention from the clinical trial staff.



Want to get **updates** about **NMO Clinical Trials?**

View our NMOtion website at:
www.nmotion.guthyjacksonfoundation.org

The Guthy-Jackson Charitable Foundation Clinical Trial Position Statement

The Guthy-Jackson Charitable Foundation (GJCF) supports efforts directed at the prevention, diagnosis, treatment and cure of neuromyelitis optica (NMO) and NMO spectrum disorders. It facilitates scientific and clinical advances directed toward these goals.

The GJCF endorses clinical trials aimed at improving the health of NMO patients. **It neither sponsors nor conducts clinical trials, nor does it advocate for any specific therapeutic candidate or endorse any particular clinical trial design.** The GJCF **plays no role** in the active enrollment of subjects in clinical trials, **nor does it participate** in interpreting clinical trial outcomes. The GJCF **functions neutrally and equitably** in all interactions with clinical trial sponsors, investigators and NMO stakeholders.

The GJCF facilitates access to educational resources in the public domain to provide individuals with the opportunity to learn about the latest scientific and clinical advances in NMO. By increasing awareness of these advances, including information about actively recruiting trials, the GJCF promotes informed decision-making by all members of the NMO community.

There has been an increase
in NMO research.

5.2 What research is being done to support NMO?

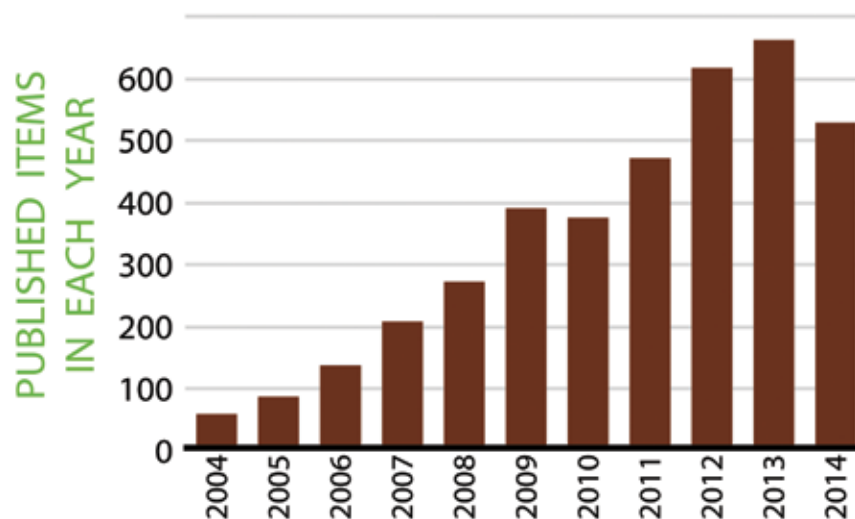
There has been an increase in NMO research.

In addition to the GJCF, the National Institutes of Health (NIH), the National Health Service (NHS) and the National Multiple Sclerosis Society (NMSS) are just three organizations among others who fund NMO research.

The GJCF has funded research to find answers that will lead to prevention, clinical treatment programs and a potential cure for NMO. These studies will increase the understanding of the disease and identify what needs to be done moving forward toward a cure. Funded researchers are asked to collaborate with

their colleagues at semiannual meetings to share research knowledge and investigate new ways to study and find a cure for NMO.

NMO Research Publications



The Guthy-Jackson Charitable Foundation Funded Scientific and Clinical Research Sites

- Brigham and Women's Hospital, Harvard Medical School
- Cleveland Clinic
- Duke University
- Johns Hopkins University
- Massachusetts General Hospital
- Mayo Clinic, Rochester

- Mayo Clinic, Scottsdale
- Mt. Sinai
- New York University
- Oxford University Medical Center
- St. George's, University of London
- Stanford University
- The Scripps Research Institute
- The University of British Columbia
- University of California, San Francisco
- University of California, Los Angeles
- University of Colorado, Denver
- University of Texas Southwestern Medical Center
- University of Utah

Visit the GJCF website at:

www.guthyjacksonfoundation.org/funding for detailed descriptions of current and completed research projects.

YOU CAN HELP find a cure for
NMO by donating to NMO science.

Visit our website to learn more:
www.guthyjacksonfoundation.org/donate



NMO Research Grant Categories

The foundation offers project funding in the following categories:

Eureka Grants

Making quantum leaps in NMO research is critical to solving this disease. Often, projects focusing on quantum leap advances are considered high-risk, but they also yield high-reward potential. These projects are unique, cutting-edge approaches that take science to another level of discovery. These projects can truly culminate in a “Eureka!” moment for NMO. Eureka Grants are funded at \$50,000 per project., and can be pre-cursors to larger follow-on studies.

CURE Grants

A Clinical Utility and Research Emphasis (CURE) Grant

focuses on a project which has clinical implications for NMO. One CURE grant spans a one-year time period with a \$100,000 budget.

Unity Grants

Unity Grants join two (or more) Principal Investigators from separate institutions working together on one NMO research project.



Make a Financial Donation to NMO Research

You or someone you know can make an impact in the world of NMO by funding NMO science projects. 100 percent of all donations go directly to scientific

To advance NMO research, GJCF established a **biorepository** (also known as a “blood bank”) at the Accelerated Cure Project (ACP). Specimens were collected from 2008 - 2012. In 2013, GJCF expanded the biorepository to the Data Coordinating Center at the University of Utah and the **Laboratory Corporation of America (LabCorp)**. This effort enables approximately 70 full service patient draw sites, and hundreds of additional donor sites **in the continental United States**.

Collecting patient data and specimens over time is critical to better understand NMO including cause, epidemiology, relapse rates, best treatments, and similar factors. **De-identified (meaning no identifiable patient information other than a barcode) biospecimens and data** from volunteer patients and controls are uniformly and **confidentially** collected and stored in the **biorepository**.

The biorepository is a powerful resource to discover patterns in the course of a disease that are not obvious from any one individual.



The biorepository is a powerful resource to discover **patterns** in the course of a disease that are not obvious from any one individual. A **long-term observation** of a disease among a large group of patients and controls is called a **natural history study**. Researchers can examine factors that influence disease prognosis and quality of life, describe patient care patterns, assess effectiveness, safety, or toxicity of treatment, and study other outcomes measures. **NMO biorepositories may also lead to clinical trials to identify potential improvements in treatment. NMO biorepositories may support new discoveries or help to solve unanswered questions including:**

- Is there a “typical” course of NMO, or does it vary in each individual?
- How does geography or season relate to the disease course, if at all?
- Does a treatment lead to long-term benefits, such as fewer relapses?
- How is NMO severity or disability affected by new or existing therapies?
- What are the significant predictors of favorable versus poor outcomes?
- What is the safety profile of a specific therapy?
- How do NMO clinical practices vary, and what are best practices for managing NMO?
- Are there differences in the delivery and/or outcomes of care for NMO?

Patients are critical in the effort to find a cure for NMO. **Biospecimens may ultimately serve to identify the best possible diagnosis and management of**

Patients are critical in the effort
to find a cure for NMO.

each NMO patient, and find new and more effective treatments.

NMO patients and qualified controls can **participate in research** to help solve NMO. Joining the biorepository effort and helping to raise awareness are simple ways to contribute to the cause.

5.5 Donating to the Blood Bank - How does it work?

Urgent Need

Because NMO is a rare disease there is an urgent need for every patient to participate in the effort to solve this disease. Only a **limited amount** of NMO blood samples are currently available worldwide. NMO patients and qualified controls can help meet this urgent need by donating samples and raising awareness of the repository program. **It’s an easy way to make an important difference in NMO research and accelerate a cure.**

NMO patients and
blood relatives can HELP!
DONATE TO THE BIOREPOSITORY
Learn how on page 180



If you or a family member have been diagnosed with NMO, please help by donating blood for NMO research.

The Donation Process

Once you volunteer to join the biorepository program (see section “How to Donate” on page 180), **you will be contacted by a clinical research coordinator (CRC) to begin the process.** Participating in the NMO repository is **confidential.** The CRC will explain the repository program and answer any questions you may have. If you qualify and consent to participate, you and the CRC work together to schedule the time and location for your blood draw. Prior to your first blood draw appointment you will receive an enrollment packet in the mail. Questions about your lifestyle, environment, location, medical history and health status will be asked. By providing information in advance you help to **speed NMO research.** These **valuable data** are collected and **de-identified** to protect your confidentiality.

Because NMO is a rare disease
there is an urgent need for every
patient to participate in the effort
to solve this disease.

Researchers who apply for and receive samples from the biorepository agree to provide results from their research for inclusion in a database made available to other researchers.

How to donate

QUICK READ

Donations can be made via:

- Home Base Sites
- LabCorp sites
- NMO Patient Days

The NMO biorepository works in association with Home Base Centers, LabCorp and the Utah Data Coordinating Center where NMO advocates come together donate valuable NMO blood samples and data for research. **NMO subjects have three donation options:**



- 1. Home Base Centers:** Part of the GJCF Collaborative International Research in Clinical and Longitudinal Experience for NMO Studies (CIRCLES) study program, Home Base Centers are regional university sites where neighboring NMO patients and qualified controls can **donate** blood samples and data. Volunteers who donate must first contact their regional Home Base to start the process. Find new **Home Base Centers** as they are added at: www.nmotion.guthyjacksonfoundation.org
- 2. LabCorp Sites:** If the volunteer is qualified, the Home Base coordinator directs volunteers to a

selected LabCorp site to donate blood. There are many LabCorp collection sites in the contiguous United States where subjects may go to donate samples.

- 3. NMO Patient Days:** These events occur at regional Home Base Centers across the United States as well as the annual GJCF NMO Patient Day in Los Angeles, CA. Please visit: <http://www.guthyjacksonfoundation.org/conference-landing-page/> for a list of an NMO Patient Day closest to you.

Schedule your donation appointments now at these Regional Home Bases:



Western Region

Dharti (Dorothy) Trivedi, Clinical Research Coordinator
Phone: 650-796-8420
Email: dtrivedi@stanford.edu

Central Region

Ruth Johnson, Professional Research Assistant
Phone: 303-724-7885 (Office)
Email: ruth.johnson@ucdenver.edu

Eastern Region

Regina Brock-Simmons, RN, BS
Phone: 410-502-7220 (Office)
Email: rbrockl@jhmi.edu

CANADA

University of British Columbia

Katrina McMullen
Katrina McMullen
Djavad Mowafaghian Centre for Brain Health
2215 Wesbrook Mall
Vancouver, BC V6T 1Z3
NMO Clinic: 604-822-7131
NMO Research: 604-822-3598



5.6 NMO International Clinical Consortium (ICC)

The number of patients followed at any one site is generally too small to study all aspects of the disease. To meet this challenge, GJCF formed an **International Clinical Consortium (ICC) and Biorepository** program with representative international centers. These centers work together in collaboration to apply uniform disease definitions, clinical assessment tools, and research advances. **The goal of this consortium is to create a multi-center collaboration for sharing clinical and biological data from NMO patients.**

The goal of this consortium is to create a multi-center collaboration for sharing clinical and biological data from NMO patients.



5.7 International Panel for Neuromyelitis Optica Diagnosis (IPND)

Formed in 2011 and funded by The Guthy-Jackson Charitable Foundation, the **International Panel for Neuromyelitis Optica Diagnosis (IPND)** is a group of scientists and clinicians whose work updated the 2006 diagnostic criteria for NMO and NMOSD to 2015.

The IPND addresses the following key issues:

1. NMO/SD: definitions and diagnostic criteria
2. How opticospinal MS may differ from NMO or MS
3. Potential biomarker candidates for specific differential diagnosis of NMO
4. NMO in relation to other autoimmune diseases
5. Role of serological testing in diagnosis
6. Role of radiology in diagnosis



Do you know?

**IT'S EASY TO FIND AN
NMO CLINICIAN**

on the GJCF's website.

Visit www.guthyjacksonfoundation.org
to find your nearest NMO clinician.

Resources & Support



Resources & Support

- 6.1 What is NMotion?
- 6.2 Join the NMO Advocacy Network
- 6.3 NMO Online Educational Program
- 6.4 Patient Stories
- 6.5 Support Groups & Advocacy Organizations
- 6.6 Suggested Reading
- 6.7 The Bookshelf
- 6.8 NMO Library & Spectrum
- 6.9 NMO TV

6.1 What is NMotion?

NMOtion (pronounced “in motion”) is a GJCF website where you can get involved to help cure NMO. On NMotion you can sign up to receive information about NMO clinical trials, opportunities to advocate for NMO and how to participate in the GJCF NMO bioepository (refer to section 5).

Get in motion to cure NMO

NMOtion



Learn



Join



Teach



Advocate



Share

6.2 Join the NMO Advocacy Network

The only requirement for becoming an advocate is persistence and the desire to make a difference in the lives of those living with NMO.

Who is an advocate?

Advocates are patients, caregivers, friends, family, community organizations, research and medical professionals, and any member of the public who raises awareness or works to find a cure for NMO.

What is an advocate's role?

Advocates work individually or as a group with established organizations to **build awareness** in their local areas. Efforts can include anything from fundraisers, events and meetings to bake sales, car washes and

more. An advocate may be asked to speak to a group of people who are interested in learning more about NMO.

For additional event ideas visit the NMOtion website at: <http://nmotion.guthyjaksonfoundation.org/>



How does GJCF support advocacy?

Advocates who are interested in hosting a community event may request an NMO Share Package that generally contain the following:

- Items from the NMO Shop
- Brochures
- Clinical Trials Information Card

NMO / MS...What You Need to Know Brochure

Help spread awareness about NMO!

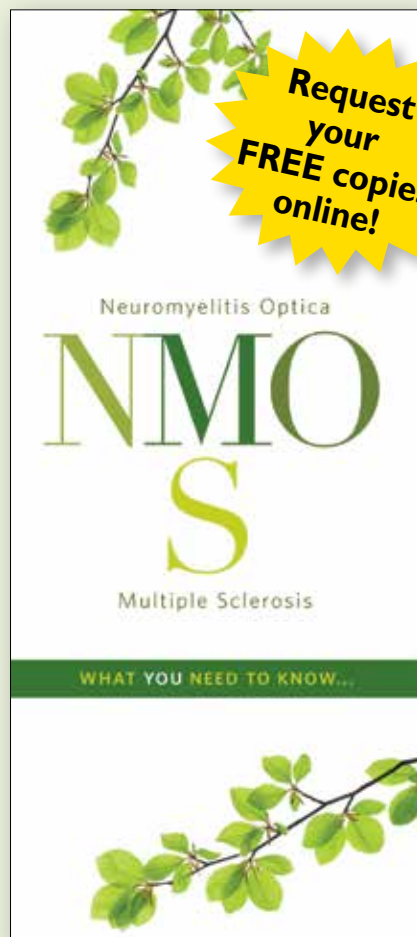
The *NMO/MS What You Need to Know* brochure offers patients, advocates and healthcare professionals additional resources to assist in considering NMO as a possible diagnosis.

Anyone can order these brochures. It's a great way to help educate:

- Clinicians
- Friends
- Nurses
- Event attendees
- Family
- Anyone else you can think of!

Request your free copies online at:

www.guthyjaksonfoundation.org/nmo-ms-what-you-need-to-know



- CD including:
 1. GJFC fact sheet
 2. NMO Clinical Trial Information Card
 3. NMO fact sheet
 4. NMO repository fact sheet
 5. Rare disease fact sheet
 6. PowerPoint presentation about NMO and GJCF
 7. GJRFI Giving Form for financial donations

- DVD with videos about NMO

NMO / MS...What You Need to Know Brochure

Spread awareness about NMO!

The *NMO/MS What You Need to Know* brochure offers patients, advocates and healthcare professionals additional resources to assist in considering NMO as a possible diagnosis.

Anyone can order these brochures. It's a great way to help educate:

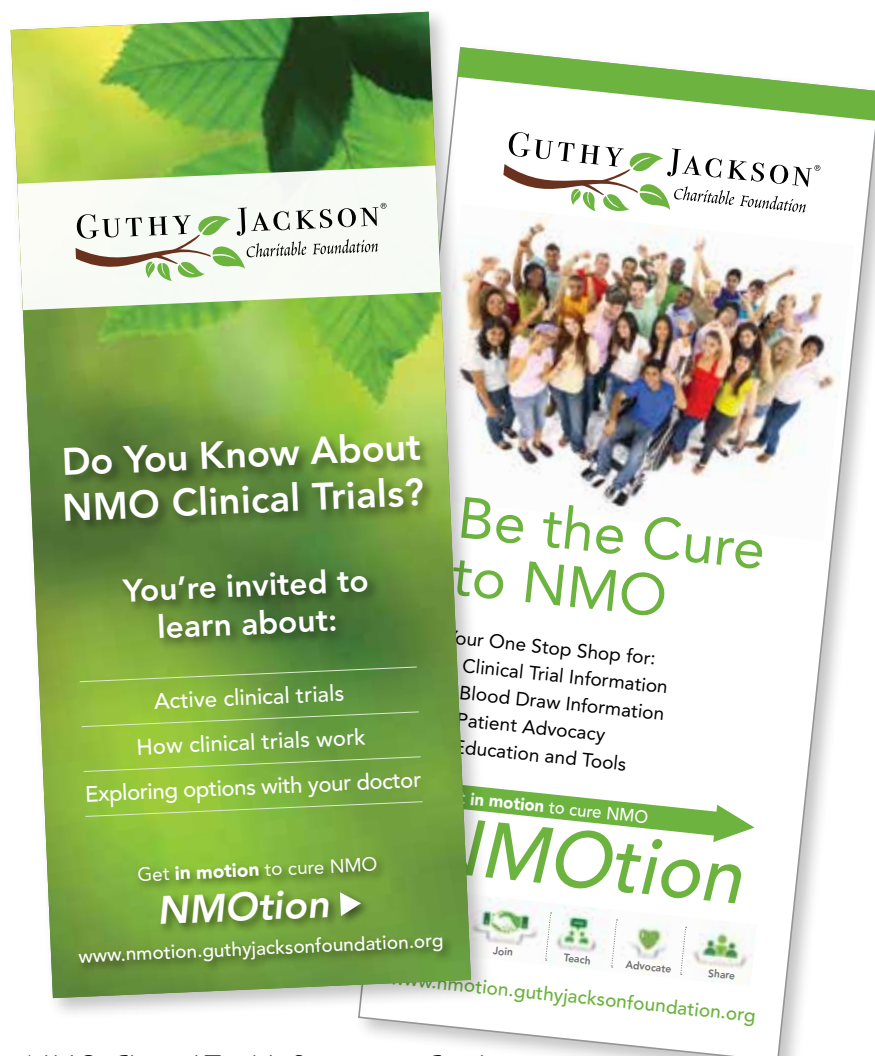
- Clinicians
- Friends
- Nurses
- Event attendees
- Family
- Anyone else you can think of!

Request your free copies online at:

www.guthyjacksonfoundation.org/nmo-ms-whatyouneed-to-know

NMO Clinical Trial Information Card

Did you know that there are no current Food and Drug



NMO Clinical Trial Information Card

Administration (FDA) approved therapeutics for NMO? For a therapeutic to be approved for NMO, the FDA requires clinical trial testing. There are a number of new NMO clinical trials underway seeking to establish specific treatments for NMO patients. To help raise awareness about NMO clinical trials, GJCF has produced an **NMO Clinical Trial Information Card** for the NMO community, which is shipped to **NMO Advocates** in the “NMO Share Package” free of cost. Visit www.nmotion.guthyjacksonfoundation.org to become an **Advocate and start raising awareness for NMO today.**

6.3 NMO Online Educational Program

Helping to inform the NMO community about research and clinical trials, GJCF hosts online educational **webinars** and **podcasts**. NMO clinicians, scientists and industry delegates discuss clinical trials, how they work and what they might mean for NMO, as well as relevant topics in NMO research and education.

LOCATE RECORDINGS OF
NMO Clinical Trial
webinars and podcasts
by visiting NMOtion at:
www.nmotion.guthyjacksonfoundation.org



6.4 Patient Stories

Oftentimes, nothing speaks louder than genuine, real-life accounts of people living with a rare disease. **Personal narratives are an essential part of building upon communication, interpreting experiences and incorporating new information.** On the NMotion site, the “Patient Stories” section offers reassurance and support from personal experiences shared by patients living with NMO.

Visit NMotion at: nmotion.guthyjacksonfoundation.org/ to share or read stories shared by our patient community.

6.5 Support Groups & Advocacy Organizations

The GJCF places a high value on its relationships with advocacy organizations in support of providing information, education and resources for those living with NMO. Joining a support group may be beneficial to NMO patients, caregivers, family and friends. New NMO support groups are being established all over the world. **There are different types of NMO support groups ranging from in-person to telephone and online communities.** You can access information about NMO support groups on the Advocate page on the NMotion website at: nmotion.guthyjacksonfoundation.org/advocate. Here you will find advocacy organizations that provide support for the NMO community.



American Foundation for the Blind

2 Penn Plaza, Suite 1102
New York, NY 10121
Tel: (212) 502-7600
Fax: (888) 545-8331
Website: <http://www.afb.org/>

**Christine Ha
The Blind Cook**

Website: <http://www.theblindcook.com/>
Website: www.christineha.com

CoachArt

3303 Wilshire Boulevard
Suite 230
Los Angeles, CA 90010
Website:
<http://www.coachart.org/>
Tel: 213-736-2850
Fax: 213-736-2851

Craig Photography

Website:
<http://craig-photography.blogspot.com/>

**The Jennifer Jaff Center –
Chronic Illness Advocacy**

195 Farmington Ave.
Suite 306
Farmington, CT 06032
Tel: 860-674-1370
Fax: 860-404-5127
Website: <http://www.thejenniferjaffcenter.org/>
Email:
info@thejenniferjaffcenter.org

Myelin Repair Foundation

18809 Cox Avenue, Suite 190
Saratoga, CA 95070
Tel: 408-871-2410
Fax: 408-871-2409
Website:
<http://www.msfocus.org/>
Email: info@myelinrepair.org

**National Eye Institute
(NEI)**

National Institutes of Health,
DHHS
31 Center Drive
Rm. 6A32 MSC 2510
Bethesda, MD 20892-2510
Tel: 301-496-5248
Website:
<http://www.nei.nih.gov/>
Email: 2020@nei.nih.gov

**National Institute of
Neurological Disorders
and Stroke (NINDS)**

P.O. Box 5801
Bethesda, MD 20824
Tel: 800-352-9424
Email: braininfo@ninds.nih.gov
Website:
<http://www.ninds.nih.gov/>

**National Organization for
Rare Disorders (NORD)**

P.O. Box 1968
(55 Kenosia Avenue)
Danbury, CT 06813-1968
Tel: 203-744-0100
Voice Mail:
800-999-NORD (6673)
Fax: 203-798-2291
Website:
<http://www.rarediseases.org/>
Email: orphan@rarediseases.org

**Neuromyelitis Optica UK
Specialist Services**

NMO Service
Lower Lane
Fazakerley
Liverpool L9 7LJ
Email: nmo.advice@thewaltoncentre.nhs.uk
Website:
<http://www.nmouk.nhs.uk/>

NMO Diaries

Website:
<http://www.nmodiaries.com/>

**NMO-UK Rare Illness
Research Foundation
c/o Neuro support**

Norton Street
Liverpool
L38LR
E-mail: info@nmo-ukresearchfoundation.org
Website: <http://nmo-ukresearchfoundation.org/>

**No More NMO – Riley’s
Story**

Website: <http://www.nomorenmo.com/home.html>

**Office of Rare Diseases
National Institutes of
Health**

6100 Executive Boulevard
Room 3B01, MSC 7518
Bethesda, Maryland
20892-7518
Tel: 301-402-4336
Fax: 301-480-9655
Website:
<http://rarediseases.info.nih.gov/>
Email: ord@od.nih.gov

**Oxford University NMO
Clinic Department of
Clinical Neurology**

John Radcliffe Hospital
Level 3, West Wing
Headington
Oxford OX3 9DU
UK

Tel: 01865 234461

Email: annaliza.rye@orh.nhs.uk

Website: www.nmouk.nhs.uk

**The NMO Clinical and
Research Program at UBC
Hospital and Vancouver
Coastal Health**

VCHA-UBC Hospital

2211 Wesbrook Mall

Vancouver, BC V6T 2B5

Website: <http://nmo.vchri.ca/>

**Transverse Myelitis
Association**

Chitra Krishnan:

Executive Director

1787 Sutter Parkway

Powell, OH 43065-8806

Website: <http://myelitis.org/>

**The Walton Centre NHS
Foundation Trust**

Lower Lane

Fazakerley

Liverpool

L9 7LJ

UK

Phone: 0151 525 5420

Fax: 0151 529 5500

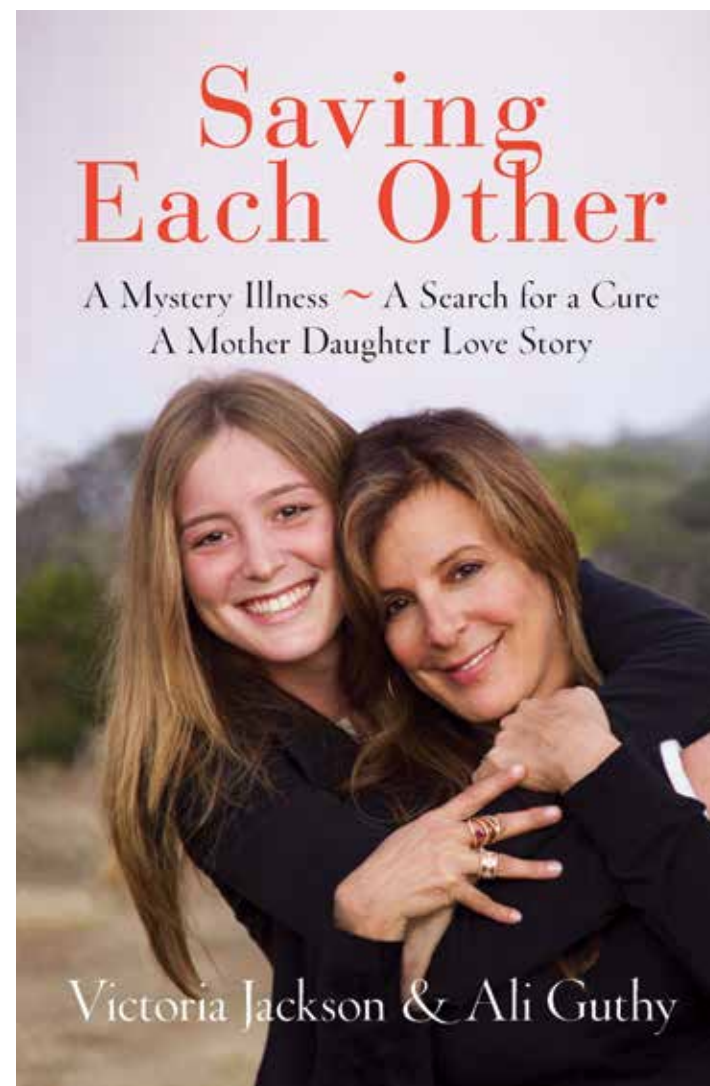
Email: [nmoAdvice@](mailto:nmoAdvice@thwaltoncentre.nhs.uk)

thwaltoncentre.nhs.uk

Website: www.nmouk.nhs.uk

**Visit the NMO Advocacy Network on NMOtion:
<http://nmotion.guthyjacksonfoundation.org/> for
the complete list of advocacy organizations.**

6.6 Suggested Reading



Saving Each Other

Authors: Victoria Jackson and Ali Guthy

In 2008, Victoria Jackson's daughter, Ali, began experiencing unusual symptoms of blurred vision and an ache in her eye. Her test results led to the diagnosis of a disease so rare, the chance that she had it was only 2%. Neuromyelitis optica (NMO) is a little understood, incurable, and often fatal autoimmune disease that can cause blindness, paralysis, and life-threatening seizures, and afflicts as few as 20,000 people in the world. At the age of 14, Ali was given a terrifying prognosis of between four to six years to live.

Saving Each Other: A Mother-Daughter Love Story begins just as Victoria and her husband Bill Guthy learn of Ali's disease, starting them on a powerful journey to save Ali, their only daughter, including bringing together a team of more than fifty of the world's leading experts in autoimmune and NMO-related diseases to create The Guthy-Jackson Charitable Foundation, which aims to find a cure for NMO.

**100% of all profits directly support
scientific and clinical research for
neuromyelitis optica through The
Guthy-Jackson Research Foundation, Inc.**

6.7 The Bookshelf

The GJCF welcomes diverse perspectives regarding autoimmune diseases. While it does not claim to agree with or refute their content, the following books may be of consideration for further reading:

The China Study

Author: T. Colin Campbell, Ph.D.

Referred to as the “Grand Prix of epidemiology” by The New York Times, the author examines more than 350 variables of health and nutrition with surveys from 6,500 adults in more than 2,500 counties across China and Taiwan, and suggests a connection between nutrition and heart disease, diabetes, and cancer.

The Autoimmune Epidemic

Author: Donna Jackson Nakazawa

The author suggests how “autogens” — a term denoting chemical, lifestyle, and other triggers of autoimmune disease — may influence the human immune system. Methods to protect the immune system while exploring possible causes and potential remedies for many autoimmune diseases and autoimmune-related diseases are considered.

The Balance Within

Author: Esther M. Sternberg

The author examines how stress may contribute to susceptibility to disease and its potential impact on the

Donate to NMO Science

100% OF YOUR FINANCIAL DONATION goes directly to research for NMO as directed by The Guthy-Jackson Research Foundation, Inc. Visit: www.guthyjacksonfoundation.org/donate to donate today!

immune system. She explores whether understanding of these connections in scientific terms may help to answer questions such as “does stress make you sick?”, “is a positive outlook the key to better health?”, and “how do personal relationships, work, and other aspects of our lives affect health?”

An Epidemic of Absence: A New Way of Understanding Allergies and Autoimmune Diseases

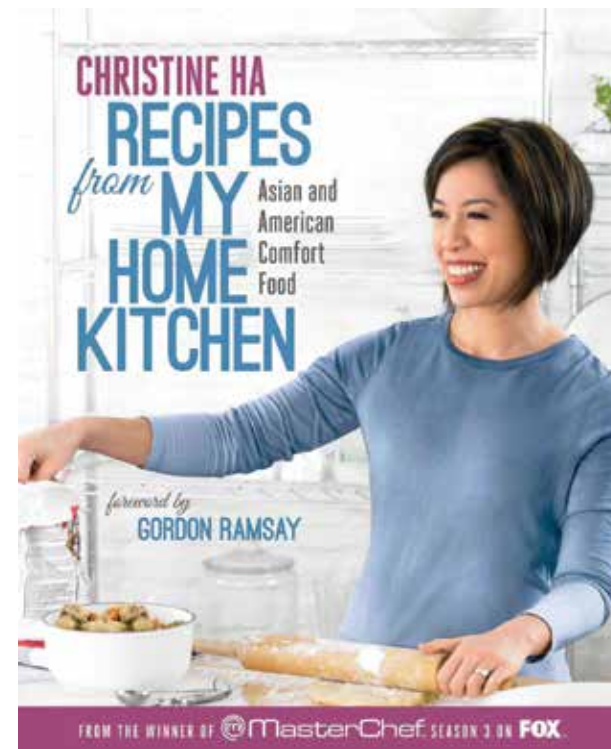
Author: Moises Velasques-Manoff

The author explores the dramatic rise of allergic and autoimmune diseases and the controversial, potentially groundbreaking therapies that scientists are developing to correct these disorders. The author’s exploration includes the “worm therapy,” probing the link between autism and a dysfunctional immune system, asking what will happen in developing countries regarding allergic disease and more.

Recipes from My Home Kitchen: Asian and American Comfort Food

Author: Christine Ha

Winner of Masterchef Season 3, in her kitchen, Christine Ha possesses a rare ingredient that most professionally-trained chefs never learn to use: the ability to cook by sense. After tragically losing her sight in her twenties, this remarkable home cook, who specializes in the mouthwatering, wildly popular Vietnamese comfort foods of her childhood, as well as beloved American standards that she came to love growing up in Texas, re-learned how to cook. Using her heightened senses, she turns out dishes that are remarkably delicious, accessible, luscious, and crave-worthy.



6.8 NMO Library & Spectrum

The Guthy-Jackson Charitable Foundation's online **NMO Library is one of the largest collections of scientific and clinical NMO abstracts.** Every day, researchers are making more discoveries about NMO. Learn about key topics like antibodies, aquaporins, astrocytes, therapies and much more. Inside the NMO Library you will find also find a collection of topics ranging from diet and nutrition to autoimmunity in the forms of:

- **Scientific abstracts**
- **Videos**
- **Press articles**
- **Books**

NMO Library: Helpful NMO Publications for Clinicians, Scientists & Patients

Treatment of Neuromyelitis Optica: Review and Recommendations

Abstract

Neuromyelitis optica (NMO) is an autoimmune demyelinating disease preferentially targeting the optic nerves and spinal cord. Once regarded as a variant



The Guthy-Jackson Charitable Foundation's online NMO Library is one of the largest collections of scientific and clinical NMO abstracts.

of multiple sclerosis (MS), NMO is now recognized to be a different disease with unique pathology and immunopathogenesis that does not respond to traditional MS immunomodulators such as interferons. Preventive therapy in NMO has focused on a range of immunosuppressive medications, none of which have been validated in a rigorous randomized trial. However, multiple retrospective and a few recent prospective studies have provided evidence for the use of six medications for the prevention of NMO exacerbations: azathioprine, rituximab, mycophenolate mofetil, prednisone, methotrexate and mitoxantrone. This review provides a comprehensive analysis of each of these medications in NMO and concludes with a set of recommended consensus practices.



Integrative Continuum: Accelerating Therapeutic Advances in Rare Autoimmune Diseases

Abstract

Autoimmune diseases are chronic, life threatening, and of burgeoning public health concern. They rank among the 10 most common causes of death in women, and some have incidence rates surpassing those of heart disease and cancer. Emerging information regarding molecular and cellular mechanisms affords opportunities for the discovery of novel therapeutic strategies or the repurposing of FDA-approved pharmacologic agents. Yet, obstacles to drug development amplify as an inverse function of the incidence of rare autoimmune disease; challenges include heterogeneous clinical presentation, paucity of definitive biomarkers, and poorly validated measures of therapeutic response. An integrative continuum model to address these challenges is being applied to neuromyelitis optica (NMO)—a potentially devastating neurodegenerative process that has had limited therapeutic options. This model links target discovery with pharmacologic application to accelerate

**Help educate medical professionals
by downloading and sharing
NMO scientific papers and abstracts
from the NMO Library.**

improved clinical efficacy. The application of such innovative strategies may help researchers overcome barriers to therapeutic advances in NMO and other rare autoimmune diseases.

Visit the NMO Library now to download papers and abstracts to share with clinicians, family and friends at: <http://spectrum.guthyjacksonfoundation.org/nmo-library/>

Online Community – Spectrum

Spectrum is an online community where advocates, patients, caregivers, researchers, and all stakeholders can:

- Locate the largest single source of abstracts for NMO studies online
- Connect with others in the NMO community
- Share NMO experiences and follow the journeys of other patients and caregivers
- Learn the latest research and clinical studies focusing on NMO
- Find clinical trials in which patients can participate
- Experience a growing online repository of all things NMO-related from materials to patient stories to the latest patient advocacy trends

Join us online at:

www.spectrum.guthyjacksonfoundation.org



6.9 NMO TV

Aimed at helping the NMO community have the latest information at its disposal, **NMO TV** showcases the foundation's growing NMO video library. Informational videos about different aspects of living with NMO are easily viewed along with relevant topics suggested to help expand your understanding about topics like scientific research, managing stress and fatigue, NMO FAQs, and much more. Visit www.guthyjacksonfoundation.org/nmo-tv to view the collection of videos about NMO.

Directory of Clinicians

The Guthy-Jackson Charitable Foundation is “Connecting the Docs” by compiling a worldwide list of clinicians who treat NMO.



Directory of Clinicians “Connect the Docs”

With NMO being a rare orphan disease, simply finding a clinician who treats NMO can be difficult. To help patients find NMO clinicians, The Guthy-Jackson Charitable Foundation is “Connecting the Docs” by listing known clinicians who treat NMO. On the foundation’s website you will find a map with locations of NMO clinicians. Thus far, **close to 200 clinicians** have been mapped all over the world and our list continues to grow.

The following pages contain an abbreviated list of “**Connect the Doc.**” If you receive treatment from or know of an NMO clinician(s) who you do not see in this list, please visit our website to find out if the clinician(s) is on our online map. If you would like to “connect a doc” by submitting information about a clinician who treats **NMO please visit our web page at:**
<http://www.guthyjacksonfoundation.org/mapping-nmo/>

Alabama

Emily Riser, MD

The Tanner Center for MS
509 Brookwood Blvd.
Birmingham, AL 35209
Phone: (205) 803-2210
Fax: (205) 803-2214

Jayne Ness, MD, PhD

Children's Hospital of Alabama
1600 7th Ave. South, CHB
Suite 314
Birmingham, AL 35233
Phone: (205) 996-7850
Fax: (205) 996-7850

Christopher Eckstein

Neurology Child and Adult
100 Memorial Hospital Dr.
Mobile, AL 36608
Phone: (251) 344-2762
Fax: (251) 344-5492

Fritz A Lacour, MD, FAAN

Neurologist
Diagnostic and Medical Clinic
1720 Spring Hill Avenue,
Suite 300
Mobile, AL 36604
Phone: (251) 435-1200
Fax: (251) 633-2330

Nirmala Aryal, MD

Neurologist
Arizona Neurological Institute
10240 W. Indian School Rd.
Bldg I, Suite 115
Phoenix, AL 85037

Arizona

Dean Wingerchuk, MD

Mayo Clinic
13400 E. Shea Blvd.
Scottsdale, AZ 85259
Phone: (800) 446-2279
Fax: (480) 301-7006

California

John A. Schafer, MD

Mercy MS Center
6555 Coyle Avenue
Carmichael, CA 95608
Phone: (916) 536-3670

Stephen Waldman, MD, PhD

Neurologist
Neurology Center
N. Orange County
381 E Imperial Highway
Fullerton, CA 92835
Phone: (714) 879-7200
Fax: (714) 879-3010

Charles Smith, MD

Scripps Clinic
10666 N Torrey Pines Rd.,
MS 313
La Jolla, CA 92037
Phone: (858) 554-6954
Fax: (858) 554-8202

Gregory Aaen, MD

Pediatric Neurology Children's
Hospital at Loma Linda
University
11175 Campus Street, CP
A-1108
Loma Linda, CA 92350
Phone: (909) 835-1810

Callie Momtazee, MD

UCLA Department of
Neurology
300 UCLA Medical Plaza,
Suite B-200
Los Angeles, CA 90095
Phone: (310) 825-7313

Ernestina Saxton, MD, PhD

Neurologist
6221 Wilshire Blvd., Ste. 419
Los Angeles, CA 90048
Phone: (323) 932-2575
Fax: (310) 556-4159

Mark A Montano, MD

Neurologist
New Port Doctors Medical
Group, Inc.
401 Old Newport Blvd.,
Suite 201
Newport Beach, CA 92663
Phone: (949) 999-2976
Fax: (949) 258-5524

D. Eric E Collins, MD

Neurology
Associated Neurology Medical
Group
365 Hawthorne Avenue,
Suite 203
Oakland, CA 94609
Phone: (510) 834-5778
Fax: (510) 834-0463

Benjamin Frishberg, MD

MS Center of Southern
California
3907 Waring Road
Oceanside, CA 92056
Phone: (760) 631-3000
Fax: (760) 631-3016

Ari Green, MD

UCSF MS Center/UCSF
Neuro-Ophthalmology Service
1500 Owens Street
San Francisco, CA 94158
Phone: (415) 353-2069
Fax: (415) 353-2633

Bruce Cree, MD, PhD

UCSF
1500 Owens Street, Suite 320
San Francisco, CA 94158
Phone: (415) 353-2069
Fax: (415) 353-2633

Emmanuelle Waubant, MD, PhD

UCSF Regional Pediatric Multiple Sclerosis Center, UCSF
1500 Owens Street,
Suite 320
San Francisco, CA 94158
Phone: (415) 353-2069
Fax: (415) 353-2633

Philip R. Delio, MD

Neurology Associates of Santa Barbara
219 Nogales Ave., Suite F
Santa Barbara, CA 93105
Phone: (805) 682-8153

Jeffrey Dunn, MD

Stanford Hospital & Clinics
300 Pasteur Drive
Stanford, CA 94305
Phone: (650) 723-6469
Fax: (650) 725-0390

May Han, MD

Stanford Hospital & Clinics
300 Pasteur Drive
Stanford, CA 94305
Phone: (650) 723-6469
Fax: (650) 725-0390

Colorado

Jeffrey Bennett, MD, PhD

University of Colorado
Hospital
Rocky Mountain MS Center
1635 Aurora Court
Aurora, CO 80045
Phone: (303) 724-2187
Fax: (720) 848-2106

Connecticut

Jeffrey Gross

Associated Neurologist of Southern Connecticut
75 King Highway
Fairfield, CT 06824
Phone: (203) 333-1133
Fax: (203) 333-3937

Nanci Stolgitis

CT Children's Medical Center
282 Washington Street,
Suite 2A
Dept. of Pediatric Neurology
Hartford, CT 06106

Srinath Kadmimi

Associated Neurologist of Southern Connecticut
670 Boston Post Rd.
Milford, CT 06460
Phone: (203) 877-1414

Christina J Azevedo, MD

Yale Multiple Sclerosis Center
40 Temple St, Lower Level
New Haven, CT 06510
Phone: (203) 785-4085
Fax: (603) 650-6233

Florida

Multiple Clinicians

Shands Jacksonville
Neuroscience Institute
9th Floor, Tower I 580 West
8th Street
Jacksonville, FL 32209
Phone: (904) 383-1022

William Sheremata, MD

University of Miami Health System MS Center
1150 NW 14th Street
Miami, FL 33136
Phone: (305) 243-7078
Fax: (305) 243-4678

Daniel Jacobs, MD, FAAN

Neurological Services of Orlando, P.A.
3849 Oakwater Circle
Orlando, FL 32806
Phone: (407) 240-1762
Fax: (407) 812-5869

Brian Steingo, MD

Ft. Lauderdale MS Center
572 E. McNab 2nd FL
Pompano Beach, FL 33060
Phone: (954) 738-1700
Fax: (954) 738-1666

Simon Starosta-Rubenstein, MD

Neuroscience Consultants
6200 Sunset Drive
South Miami, FL 33143
Phone: (786) 924-1311
Fax: (305) 661-1672

Peggy Coffey, MD

James A. Haley VA Hospital
13000 Bruce B. Downs Blvd.
Tampa, FL 33612
Phone: (813) 972-2000

Chetan Gandhi, MD

Multiple Sclerosis Division
Dept. of Neurology-USF
Physicians Group
12901 Bruce B. Downs Blvd.
MDC 55
Tampa, FL 33612
Phone: (813) 396-9478
Fax: (813) 905-9838

Efrain Salgado, MD

Cleveland Clinic Florida - Weston
2950 Cleveland Clinic Blvd.
Weston, FL 33331
Phone: (877) 463-2010

Georgia

Dr. Jeff English

MS Center of Atlanta
3200 Downwood Circle NW
Suite 500
Atlanta, GA 30327
Phone: (404) 351-0205

Rebecca Rahn, PA-C, MSCS

Georgia Regents Medical
Center
1120 15th Street
MS Center
Augusta, GA 30912
Phone: (706) 721-1411

Ben Thrower, MD

Medical Director
Shepherd Center
MS Institute at Shepherd
2020 Peachtree
Atlanta, GA 30318
Phone: (404) 352-2020

Hawaii

Michiko Bruno, MD

Neurology Specialist
1380 Lusitana Street, Suite 705
Honolulu, HI 96813
Phone: (808) 537-9105
Fax: (800) 537-9269

Iowa

Katherine Matthews

University of Iowa Hospitals
and Clinics
200 Hawkins Drive
Iowa City, IA 52242
Phone: (319) 356-1616

Idaho

Brad Talcott, MD, PhD

Neurologist
Driggs Health Clinic
283 North First East
Driggs, ID 83422
Phone: (208) 354-2303
Fax: (208) 354-8392

Erich W Garland, MD

Neurology, Vascular Neurology
Idaho Falls Neurology
3920 Washington Pkwy
Idaho Falls, ID 83404
Phone: (208) 227-0158
Fax: (208) 227-0159

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**Key Terms
& Facts**

**My NMO
Notes**

knowing [-ɪŋ] adj. An
|| Instruit. || Malle. 8
délibéré, intentionnel
chi, dénié, dénié
knowingly [-ɪŋli]
ment, en connais
Habilement, avec
knowledge ['nɒlɪdʒ]
it's common know
not to my know
science f.; con
thorough know
Carnal know
known [nəʊn]
knuckle ['knʌkl]
du do



Key Terms & Facts

Acute – illnesses that appear quickly and have a short, sharp course.

Antibody – a protein produced by the body's immune system when it detects harmful substances called antigens.

Antigen – any substance that causes your immune system to produce antibodies against it.

Aquaporin-4 – a protein that allows water to leave and enter certain cells in the central nervous system.

Autoimmunity – relating to an immune response by the body against one of its own tissues, cells, or molecules.

Astrocyte – a supporting cell in the central nervous system, that appears to be targeted in NMO.

Axons – a long fiber of a nerve cell that acts somewhat like a fiber-optic cable carrying outgoing messages.

Blood-Brain Barrier (BBB) – junction between the blood supply and the central nervous system that regulates what comes in and out.

Brain stem – junction that connects the brain with the spinal cord.

Central nervous system (CNS) – the brain and spinal cord.

Complement – the group of proteins in normal blood serum and plasma that in combination with antibodies causes the destruction especially of particulate antigens (bacteria and foreign blood corpuscles).

Demyelination – the breakdown of the myelin sheath.

Fatigue – extreme tiredness.

Immune system – the various cells and organs that protect the body from viruses, bacteria and other illness.

Immunosuppressant – medication that purposefully weakens the immune system.

Inflammation – a protective attempt by the organism to remove the cause of damage and to initiate the healing process.

Longitudinally Extensive Transverse Myelitis (LETM) – an inflammatory and demyelinating attack on the spinal cord causing symptoms.

Monophasic – a disorder with a single phase or stage.

Myelin – a protective covering around a nerve, speeding up the transfer of electrical messages.

NMO-IgG – autoantibody marker that targets the water channel protein aquaporin-4 causing NMO.

Optic neuritis (ON) – an inflammatory and demyelinating attack on the optic nerve, causing visual symptoms.

Relapse – a new “attack” of NMO, which can affect optic nerves, spinal cord or brain/brainstem.

Repository – a location where de-identified samples such as blood and other biological specimens and clinical data from donors are confidentially stored.

Symptom – an impairment that is left after recovery from a relapse, for example pain or reduced vision.

Transverse myelitis (TM) – a neurological disorder caused by inflammation across both sides of one level, or segment, of the spinal cord.

White blood cells – the group of cells within the blood that regulate the immune system and mount the immune response to illness.

NMO Facts at a Glance

- **1804:** Dr. Antoine Portal publishes an **early case of disease** consistent with NMO.
- **1870: Sir Thomas Allbutt, M.D.**, initially describes a case of simultaneous optic neuritis and transverse myelitis that does not have obvious brain tissue involvement.
- **1894:** Eugène Devic, M.D., coins the term “neuromyéélite optique,” or **neuromyelitis optica**.
- **2006:** Vanda A. Lennon, M.D., Ph.D. and colleagues at the Mayo Clinic identify the NMOIgG antibody as being correlated specifically with NMO disease.
- Among patients with relapsing NMO, **roughly 50 percent** will have a relapse in the first year, **75 percent** by the third year and **90 percent** by the fifth year.
- People with **monophasic** (single attack) NMO, which is much less common than **relapsing NMO**, tend to have more severe attacks than those with the relapsing NMO; approximately 20 percent of patients have permanent vision loss, and 30 percent have permanent paralysis in one or both legs.
- Approximately **60 - 70 percent** of NMO patients have **detectable antibodies** (immune proteins) in their blood that target protein that channels water in and out of cells existing primarily in the brain and spinal cord called aquaporin 4 (AQP4).

- About **80 percent** of patients with NMO have distinct, **long lesions in the spinal cord** on MRI that are not typically present in patients with MS.
- An antibody, called **NMO-immunoglobulin G (NMO-IgG)**, is present in the blood of approximately 70 percent of NMO patients. Patients appropriately diagnosed with MS do not usually test positive for NMO-IgG (see section 1.6).
- **NMO is more common in women than men**, with a ratio of approximately **6:1**.
- The **median age of onset is between 32 and 40** years of age, based on reports from different regions of the world.
- Previous reports estimate up to **one-half million cases worldwide**.
- **Global statistics** on the prevalence of NMO has yet to be determined.
- Currently, NMO in the United States is estimated to affect approximately **1 in 25,000** people (estimates may vary depending on ethnic background).
- In the U.S., the National Institutes of Health (NIH) classifies NMO as a rare orphan disease (fewer than 200,000 people affected). **It is estimated that NMO affects at least 4,000 people in the U.S. alone. Worldwide, NMO is likely to affect tens of thousands of people based on prevalence rates in other countries.**

- NMO is one of roughly **7,000 rare diseases** that affect about **25 million people in the U.S.** alone, according to the NIH.
- Worldwide, only about **20 families** with more than one case of NMO have been reported.

My NMO Notes

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.[illegible]

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Acknowledgments

Our goal is to provide insight to NMO, a rare and misunderstood disease. If this booklet provides new information and/or guidance, we will have fulfilled our objective.

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About Us

The Guthy-Jackson Charitable Foundation is dedicated to funding basic science research to find answers that will lead to the prevention, clinical treatment programs and a potential cure for NMO.

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