Understanding MOGAD,

the Journey Ahead, and the Community and Resources to Support YOU!

Understanding MOGAD and the Path Ahead

Whether you just received a diagnosis or are waiting to confirm if it's myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD)*, this can be a difficult time in your life.

The MOGAD community includes healthcare professionals, researchers, and support groups all working together to advance treatments.

> "You may not feel okay today... that's okay. Heal at your own pace, in your own ways, at your own time. You got this, hummingbird warrior. I'm proud of you for braving through everything in your way."
>
> - Francis

In this brochure, you will find information on the common signs and symptoms, diagnostic process, and what to expect in terms of disease management.

*Myelin oligodendrocyte antibody-associated disease is also known as myelin oligodendrocyte antibody disease by some experts and both mean the same condition.

Overview of MOGAD

MOGAD Defined

MOGAD is a rare condition that causes inflammation, or swelling, of the central nervous system – the optic nerve, brain, and/or spinal cord.[1]

MOGAD is thought to be caused by autoantibodies, which are antibodies in your immune system that mistakenly target healthy proteins in the body instead of harmful pathogens.[1]

In MOGAD, these antibodies are called myelin oligodendrocyte glycoprotein (MOG)-IgG and they damage MOG protein located on the outer surface of the myelin sheath, a protective coating on your nerve tissue in the central nervous system.[1]

MOGAD has evolved as a distinct disease separate from multiple sclerosis (MS) and neuromyelitis optica spectrum disorder (NMOSD).[2]

"A neuroimmunologist once told me that knowledge is power and **WE** are in a position of strength because **WE** have a diagnosis." - Jenny

Disease Course

MOGAD presents as a sudden onset of symptoms, also known as an attack, that range in type and severity.[2] The disease can be multiphasic, meaning additional attacks occur after the initial episode.[2] It can also be monophasic, where there is only one episode of an attack over a lifetime.[2]

If the appropriate medication(s) are taken promptly, a full or partial recovery with mild or even no disability is possible.[3] Therefore, it is important to be diagnosed and treated early. Even if the initial symptoms are mild, the nerve damage can be severe.[4]

Every year, an estimated

1.6-4.8 per million

adults are diagnosed with MOGAD.[5,6]

Scan the QR code to learn more about The MOG Project

1. cosMOG – About MOGAD. Available from: https://www.cosmogstudy.com/about-mog-ad/. Accessed on February 24, 2023; 2. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 3. Whittam et al. J Neurol. 2020;267:3565-577; 4. Jarius et al. J Neuroinflammation. 2016;13:230; 5. Orlandi et al. Mult Scler Relat Disord. 2022;63:103884; 6. De Mol et al. Mult Scler. 2020;7:806-14.

Clinical Manifestation

Clinical Manifestations of MOGAD

The symptoms of the clinical manifestations of MOGAD can vary in severity between patients.[1,2]

Optic Neuritis (ON) is the Most Common Manifestation[1]

Inflammation of the optic nerve(s) that may cause:

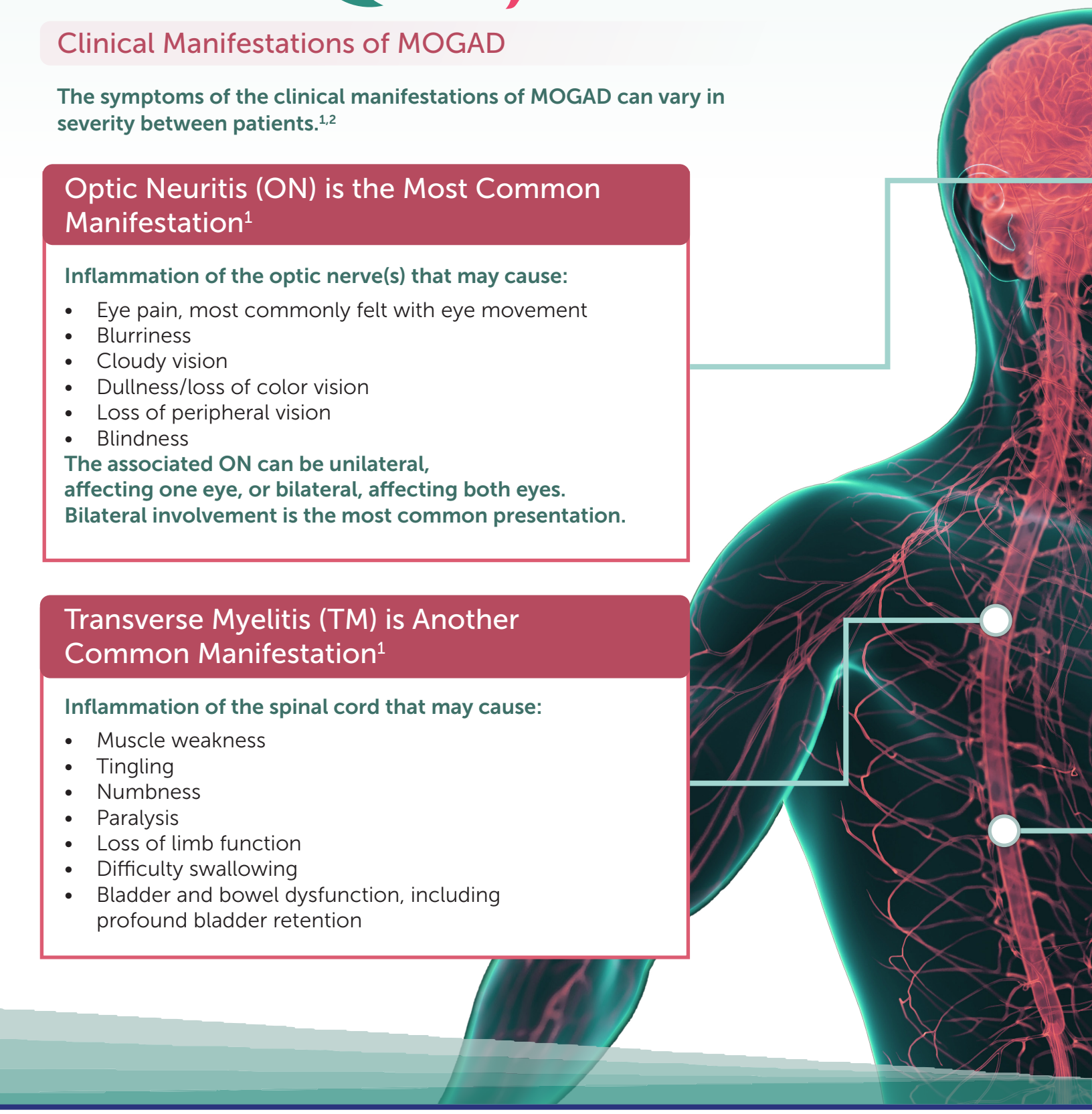
- Eye pain, most commonly felt with eye movement
- Blurriness
- Cloudy vision
- Dullness/loss of color vision
- Loss of peripheral vision
- Blindness

The associated ON can be unilateral, affecting one eye, or bilateral, affecting both eyes. Bilateral involvement is the most common presentation.

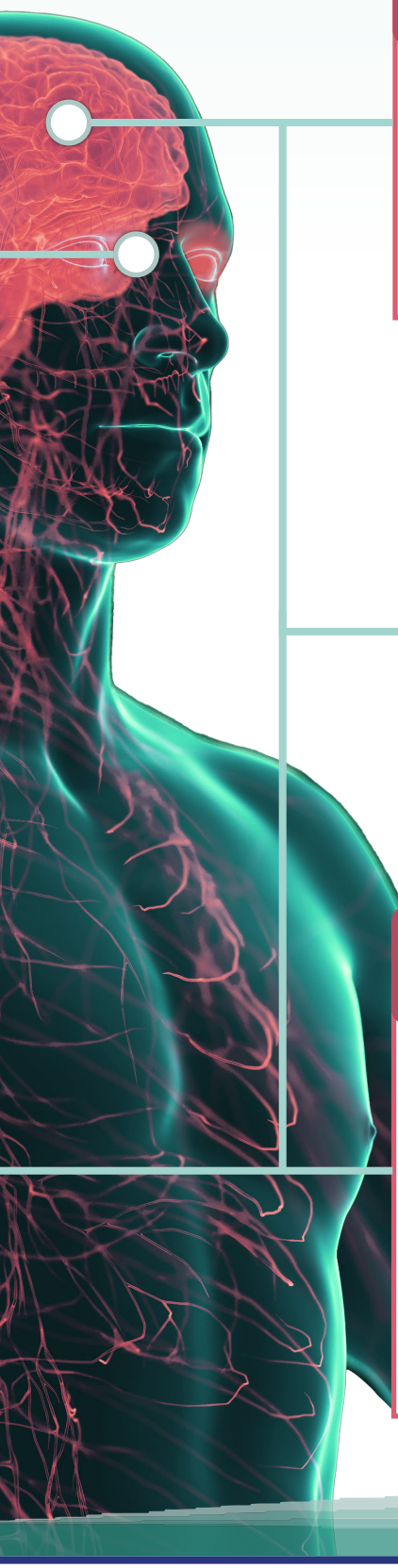
Transverse Myelitis (TM) is Another Common Manifestation[1]

Inflammation of the spinal cord that may cause:

- Muscle weakness
- Tingling
- Numbness
- Paralysis
- Loss of limb function
- Difficulty swallowing
- Bladder and bowel dysfunction, including profound bladder retention



1. Li et al. Front Aging Neurosci. 2022;14:850743; 2. Jurynczyk et al. Brain. 2017;140:3128-138.



Autoimmune Encephalitis (AE) is Another Manifestation[1]

Inflammation of the brain that may cause:

- Fever
- Impairment or loss of consciousness
- Seizures
- Difficulty coordinating movements, such as walking
- Behavioral changes

Cerebral Cortical Encephalitis (CCE) is Another Manifestation[2]

Inflammation of the brain that may be only one-sided and may cause:

- Headaches
- Seizures
- Speech impairment
- One-sided weakness
- Encephalopathy
- Fever

Acute Disseminated Encephalomyelitis (ADEM) is Less Common in Adults than ON and TM[3]

A brief but widespread attack of inflammation in the brain and spinal cord that may cause:

- Seizures
- Mild paralysis
- Difficulty walking
- Speech impairment
- Impairment or loss of consciousness
- Behavioral changes and/or confusion

ADEM is most commonly seen in children.

1. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 2. Valencia-Sanchez et al. Ann Neurol. 2022;92:297-302; 3. Li et al. Front Aging Neurosci. 2022;14:850743.

Other Symptoms

Neuropathic pain

- **Damage to the nerves causing prickling, throbbing, or sensations of burning or electrical shock.[1]**
- The pain can be chronic, meaning it persists for more than 3 months, or acute, where it resolves in less than 3 months.[1]

Unexpected and frequent fatigue that is often debilitating[2]

Severe headaches[2]

Hearing loss in a few instances[3]

Brain fog, also known as MOG fog[4]

Muscle spasms[1]

If you experience some of these symptoms, talk to your doctor immediately or visit a local emergency room, which may result in referral to a specialist, if appropriate.

Ask about MOGAD if your doctor suspects a diagnosis of any of the following neurological conditions, as they share similar signs and symptoms: Neuromyelitis optica spectrum disorder (NMOSD), multiple sclerosis (MS), acute disseminated encephalomyelitis (ADEM), autoimmune encephalitis (AE), chronic relapsing inflammatory optic neuritis (CRION), or clinically isolated syndrome (CIS).

"MOGAD is a very rare neurological disease, and it's great to have top neurologists working on ways that may help address relapses." - Jim

1. Asseyer et al. Front Neurol. 2020;11:778; 2. Jarius et al. J Neuroinflammation. 2016;13:230; 3. Tugizova et al. Mult Scler Relat Disord. 2020;41:102032; 4. Jurynczyk et al. Brain. 2017;140:3128-138.

Understanding Your Path Ahead

After a MOGAD attack, your symptoms may resolve completely or improve for a period of time. However, an estimated 50% of patients experience a recurrence of attacks, also known as a relapse.[1-4] These patients have what is known as a multiphasic disease.[2]

- The time between relapses cannot be predicted.[5]
- The number of relapses cannot be predicted.[5]

"My doctor explained that with proper treatment, I could manage future attacks."

- Dana

The most common presentation during a relapse is bilateral ON, regardless of the symptoms of the initial attack.[7]

Additionally, the risk of permanent disability is lower in MOGAD compared with NMOSD and MS as patients are more likely to have a better recovery with prompt treatment. However, the risk of disability increases with each relapse, and some patients experience more disability than others.[2]

Talk to your doctor about preventive medications, whether or not you have experienced a relapse.[2]

By learning about the signs, symptoms, and disease course of MOGAD, you can empower yourself with knowledge and be prepared for the journey ahead.

1. Akaishi et al. J Neurol. 2022;269:3136-46; 2. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 3. Jurynczyk et al. Brain. 2017;140:3128-138; 4. Salama et al. Multiple Sclerosis Rel Dis. 2019;30:231-5; 5. Li et al. Front Aging Neurosci. 2022;14:850743; 6. Ma et al. Mult Scler Relat Disord. 2020;46:102522; 7. Jarius et al. J Neuroinflammation. 2016;13:230.

Diagnosing MOGAD

If you experience some of the symptoms associated with MOGAD, some tests your doctor may order, but are not limited to, include:

- Blood test to check for the presence of the MOG-IgG antibody.[1]

If your doctor orders a blood test to check for NMOSD, ask about including a MOG-IgG antibody test.

- Magnetic resonance imaging (MRI) of the brain, optic nerves and spinal cord to check for lesions, or signs of damage.[1]
- Cerebrospinal fluid (CSF) analysis to check the chemicals and proteins in the fluid surrounding your brain and spinal cord.[1]
- Optical Coherence Tomography (OCT) to check for damage to the optic nerve.[1]
- Visual field testing to check for blind spots.[2]

Your doctor will conduct a comprehensive assessment of your signs, symptoms, and test results to determine a diagnosis/treatment plan for you.

"Each patient has a unique story, and by bonding together through organizations like The MOG Project, we learn and gain strength from each other."

- Elana

1. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 2. Jarius et al. J Neuroinflammation. 2016;13:230.

Treatment

"Quick action is needed for the best outcome."
- Andrea

The first step in treatment is to control the inflammation and symptoms associated with your attack. It is important for you to receive treatment quickly to reduce the risk of permanent disability, even if this means visiting the emergency room.[1]

Afterwards, your doctor will decide if you need to continue taking medication to prevent further attacks or relapses. This decision is individualized and can be based on the severity of your initial attack, how well you recover from the attack, and other individual health needs.[1]

At this time, there are no FDA approved treatments for MOGAD. However, some patients are experiencing success with medications, including immunosuppressants and immune modulators.[1]

There are benefits and risks associated with all medications. Talk to your doctor to determine the best treatment plan for you.

Treating a MOGAD Attack

Corticosteroids, which help reduce inflammation and suppress the immune system.[2,3]

- They may be taken orally or given as an infusion through a vein.

Plasma exchange (PLEX) may be used after corticosteroids, if needed.[3]

- It is a procedure that separates and discards the plasma component of blood that contains the harmful MOG-IgG antibody.[4]

Intravenous immunoglobulin (IVIG) may also be used after corticosteroids, if needed.[3]

- Immunoglobulins, or antibodies from healthy donors are given as an infusion through the vein.[5]

At least

50% of patients

will need multiple treatments to control their acute attack.[3]

1. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 2. Jarius et al. J Neuroinflammation. 2016;13:230; 3. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 4. National Health Service – Plasma exchange in immune-mediated neurological conditions. Available from: https://www.gosh.nhs.uk/conditions-and-treatments/procedures-and-treatments/plasma-exchange-immune-mediated-neurological-conditions/. Accessed on February 24, 2023; 5. American College of Rheumatology – Intravenous Immunoglobulin. Available from: https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Treatments/Intravenous-Immunoglobulin-IVIG. Accessed on February 24, 2023.

Medications Used to Prevent a Relapse

Intravenous immunoglobulin (IVIG)[1] or subcutaneous immunoglobulin (SCIG)[2]

- Immunoglobulins, or antibodies from healthy donors are given as an infusion through a vein, or as a self-administered injection under the skin.[2]

Immunosuppressants, which prevent your body from attacking itself[1]

- These may be taken orally, given as an infusion through a vein, or given as a self-administered injection under the skin.[1]

Oral corticosteroids

- In adults, they may be taken for a short period following an attack and sometimes taken at low doses longer term.[1]
- In children, they are not used long-term but may be given initially after treatment of an attack.[3]

You may need a combination of these medications to successfully control the disease.[1]

There are also ongoing clinical trials investigating new medications that potentially could reduce the number of relapses patients experience.

To learn more about available ongoing studies for MOGAD, see the last page of this brochure to connect with The MOG Project.

"With preventive care, my wife and I have been able to enjoy lots of travel during our retirement, including visiting our son who's living in China."

- Chuck

1. Hegen et al. Ther Adv Neurol Disord. 2020;13:1-20; 2. Sotirchos et al. Multi Scler Relat Disord. 2022;57:103462;
3. Bruijsten et al. Eur J Paediatr Neurol. 2020;29:41-53.

The MOG Project

Connect with The MOG Project and Find Support Within the MOGAD Community[1]

Founded in 2017 by Julia, a MOG patient along with her sister, Amy, and daughter, Kristina, The MOG Project is a non-profit organization devoted to supporting and advocating for patients and caregivers around the world dealing with MOGAD.

They raise awareness, educate doctors, patients, and caregivers, and advance research through expert collaboration and fundraising, in hopes of finding a cure.

Connect with The MOG Project through social media or visit their **website at https://mogproject.org**

@themogproject

On The MOG Project website, you can:

- **Connect with experts** in the field, including leading physicians and researchers.
- **Learn more about MOGAD** through podcasts and infographics.
- **Find community support** by joining virtual support group meetings, Facebook groups, and reading patient-written stories from their MOG Blog.

Navigating life with MOGAD can be difficult, but you do not have to do it alone.

1. The MOG Project. Available from: https://mogproject.org. Accessed on February 24. 2023.

This brochure was created in partnership with UCB.

Inspired by **patients.**
Driven by **science.**

THE MOG PROJECT