Back-to-School Kit
MOG Antibody Disease (MOGAD)

Below is a brief summary of the disorder affecting your student. While the presentation of symptoms may vary, this overview provides general information on the onset and impacts of the disorder. We hope this information is helpful and assists you in supporting your student as they navigate the education system while also managing their condition.

What is MOG antibody disease, and who gets it?

Myelin oligodendrocyte glycoprotein (MOG) antibody disease, or MOGAD, is an inflammatory condition that affects the brain, spinal cord, and optic nerve. MOG is a protein found on the protective layer (called myelin) covering nerves in the eye, brain, and spinal cord. In autoimmune diseases like MOGAD, the immune system mistakenly makes antibodies, proteins made by the immune system to help remove foreign materials, against normal proteins like MOG, which damages the myelin. This inflammation disrupts signals between the eye and the brain, in the brain itself, and between the brain and different parts of the body, causing a variety of health issues.

Children and young adults are more likely to develop MOGAD than other related disorders like multiple sclerosis (MS). The average age of onset is between 20-30 years old. Females and males seem to have a similar risk of developing MOGAD.

What are the initial symptoms of MOGAD, and what are the chronic symptoms those with the disorder often manage long-term?

For most rare neuroimmune disorders like MOGAD, there is an initial onset where the body attacks itself. The aftereffects of attacks can lead to life-altering long-term symptoms that the person with the condition will need to manage. If the condition is monophasic, which means it only results in one attack at the onset, the child will only need to manage the symptoms from the damage of that single attack. If the condition is recurrent, the child will have continual attacks unless an effective treatment option is found. MOGAD can be either monophasic or recurrent.

The initial attack of this rare neuroimmune disorder can include any of the following issues. Additionally, if the child does not respond well to treatment or is left untreated, the damage caused can lead to the attack being a lifelong chronic symptom.

- **Optic neuritis:** inflammation in the optic nerve that results in vision loss in one or both eyes (often both eyes in MOGAD). Those who have had optic nerve inflammation can experience residual vision loss, loss of color vision, or blurred vision. People who fully recover vision may also experience brief returns of blurred vision during times of physical or emotional stress

- **Transverse myelitis:** inflammation in the spinal cord that often causes arm or leg weakness, pain, changes in how things feel, and bowel, bladder, or sexual issues.

- **Acute disseminated encephalomyelitis:** inflammation in the brain and spinal cord, often in children, that can result in seizures, changes in behavior, mood, or thinking, and changes or loss of function in certain areas of the body

- **Cerebral monofocal or polyfocal deficits**: inflammation in one or more areas of the brain that can cause symptoms such as vision and speech problems, changes in how things feel, balance issues, and weakness in the face, arms, or legs

- **Brainstem or cerebellar deficits**: inflammation in the back or bottom of the brain that often causes double vision or issues with balance and coordination

- **Cerebral cortical encephalitis**: inflammation in the outer layer of the brain that often causes seizures, changes in thinking or behavior, stroke-like episodes, headache, or fever

What are common accommodations students with MOGAD might need to access education?

The accommodations necessary for children with MOGAD can vary depending on the severity of its impact on the child, but the following are accommodations more frequently requested by those with MOGAD:

- Longer exam periods (cognitive dysfunction may slow function)
- Ability to sit and rest when needed (there may be some mobility issues present)
- Different ways of receiving material (may need visual, audible, tactile information)
- Preferential seating (may need the ability to sit close to the teacher to keep focus)
- Schedule adjustments (may need leniency on when assignments are due)
- Ability to have access to restroom freely (may have loss of bladder control)

What does short-term treatment look like for those with MOGAD?

It's important for those with MOGAD to start treatment right away after diagnosis. Once diagnosed, the most common treatments are:

- **Intravenous steroids (methylprednisolone)**: usually the first-line therapy and is typically given for 3-5 days when symptoms causing a loss of function are present. People then usually take a decreasing amount of oral steroids over a few months to lower the risk of another attack. Most respond very well to steroids

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- **Plasmapheresis (Plasma Exchange or PLEX)**: often started in people with severe weakness or who do not recover function after steroids, but may also be started initially for those with more severe symptoms. PLEX is a process that involves the removal and return of some of a person's blood to remove harmful antibodies, including those against MOG.

- **Intravenous Immunoglobulin therapy (IVIG)**: sometimes considered in certain circumstances instead of the standard intravenous steroids and/or PLEX. IVIG is an intravenous infusion of antibodies taken from thousands of healthy people. These extra antibodies overwhelm the immune system and prevent it from attacking healthy proteins such as MOG.

What does the long-term management of MOGAD look like?

About 40-50% of individuals with MOGAD experience only one attack. MOG antibodies may decrease or even disappear over time in some cases. Research indicates that those who continue to test positive for MOG antibodies might be at a higher risk for relapse. However, subsequent attacks generally tend to be less severe. Those who have

only had a single MOGAD attack typically do not require long-term therapies, but those with a second attack often receive treatment to reduce the risk of future episodes.

For students returning to school, it's important for families to address ongoing needs like special accommodations and support for physical challenges. Long-term management for families involves coordinating with medical professionals, acquiring necessary equipment, and reintegrating into school or community activities. Understanding the emotional impact of MOGAD on children and families is important as families will need to adapt to a new way of life post-hospitalization.

Those with MOGAD may experience long-term issues such as visual issues, muscle weakness, and bladder or bowel challenges.

Mental health is also a significant consideration. Children with MOGAD might face depression or anxiety, which need to be monitored and addressed with appropriate support. A combination of education, therapy, and ongoing support helps both the child with MOGAD and their loved ones navigate the physical and emotional impacts of MOGAD.

Is MOGAD genetic or contagious?

Currently, MOGAD is not thought to be caused by any genetic or hereditary condition. It is also not thought to be contagious, nor are any of the rare neuroimmune disorders we represent.

How can people cope with a MOGAD diagnosis?

Adapting to a "new normal" is difficult, and every person with MOGAD copes differently. Some have found it easier to cope after learning more about MOGAD from their doctors and getting a better understanding of how MOGAD will affect their lives. However, some parents may choose not to keep their child informed on some of the difficult aspects of having the condition due to the age and innocence of the child. We recommend speaking with the parents of the child to determine how much the child knows about their own condition.

Learn More

SRNA
wearesrna.org

Back-to-School Kit Teacher's Guide
srna.ngo/bts-tg

More information on MOGAD
srna.ngo/mogad