

MOGmentum

SERIES #3

Let's gain MOGmentum

a collaborative series brought to you by The Sumaira Foundation for NMO and The MOG Project

ACUTE VS. PREVENTIVE TREATMENTS:

What's the difference?

ACUTE

- Acute attacks are suspected when symptoms last 24 hours or more.
- Medical tests are used to confirm the attack.
- Short-term treatment focused on decreasing inflammation (steroids) and antibody removal (IVIG, PLEX).
- Typically started immediately after initial presentation to avoid long-term damage.

PREVENTATIVE

- Long-term treatment focused on modification of the immune system to prevent relapses.
- To limit overtreatment: usually recommend to hold preventive therapy to recurrent disease (but may consider it after a single severe attack).
- Many patients are on preventive medications for years. Duration of treatment should be individualized to each patient.

MOG antibody titers can decrease with treatment but this may not indicate monophasic disease. The link between MOG antibody titers, treatment and recurring relapses remain uncertain.

COMMON TREATMENTS FOR MOGAD:

ACUTE

- IV Steroids (Intravenous Steroids)
- Oral Steroids
- IVIG (Intravenous immunoglobulin)
- PLEX (Plasma Exchange)

PREVENTATIVE TREATMENTS

- IVIG
- Azathioprine (Imuran)
- Rituximab (Rituxan)
- Mycophenolate (CellCept)

ACUTE TREATMENTS

INTRAVENOUS (IV) STEROIDS (METHYLPREDNISOLONE)

HOW IT WORKS

- Part of the drug class corticosteroids.
- Acts as an anti-inflammatory agent to slow the body's response to injury or disease, including reducing swelling and inflammation.
- Also works by reducing the activity of the immune system.

DOSING & ADMINISTRATION

- Adult dosage: 1g daily.
- Pediatric dose: 20-30 mg/kg body weight daily.
- Administration: usually given by IV over 3-5 days followed by a gradual taper to allow adrenal glands time to recover.
- Tapering updates to follow doctors directions.
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- In some cases, patients will be hospitalized for the course of their treatment, others receive infusion via outpatient services.
- Can address symptoms as early as 2-3 days however recovery from damage varies.
- Your doctor may give medication to reduce excess stomach acid.

POTENTIAL SIDE EFFECTS

- Common: nausea, vomiting, heartburn, headache, dizziness, restlessness, fluid retention, trouble sleeping, appetite changes, increased swelling, and pain/swelling/redness at injection site.
- Serious: high blood sugar, high blood pressure, cardiac irregularities, severe muscle weakness post treatment, and irritability or other mood changes.

SPECIAL CONSIDERATIONS

- May interact with other commonly prescribed medications including warfarin, aspirin and NSAIDS such as ibuprofen (Advil) and celecoxib (Celebrex).

ACUTE TREATMENTS

ORAL STEROIDS (PREDNISONE, METHYLPREDNISOLONE)

HOW IT WORKS

- Oral, synthetic corticosteroid.
- Acts as an anti-inflammatory agent to slow the body's response to injury or disease, including reducing swelling and inflammation.
- Also works by reducing the activity of the immune system.

DOSING & ADMINISTRATION

- Dosage: varies widely based on individual patient factors and doctor preference.
- Some centers use high-dose oral steroids as equivalent to IV
- Administration: high-dose usually 3-5 days, followed by oral taper to prevent rebound inflammation and allow adrenal glands time to recover.
- Tapering updates to follow doctors directions
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- Can address symptoms as early as 2-3 days however recovery from damage varies.
- Your doctor may give medication to reduce excess stomach acid.

POTENTIAL SIDE EFFECTS

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- Serious: high blood sugar, high blood pressure, cardiac irregularities, severe muscle weakness post treatment, and irritability or other mood changes.

SPECIAL CONSIDERATIONS

- May interact with other commonly prescribed medications including warfarin, aspirin and NSAIDS such as ibuprofen (Advil) and celecoxib (Celebrex).
- Must be careful with steroids in children due to risk of growth delay

Let's take a break to talk

STEROID TAPERING & LONG-TERM USE

- Most MOG-AD experts recommend a slow oral taper to prevent rebound inflammation (4-6 weeks, sometimes longer, depending on patient response and other factors).
- After about 2 weeks of steroids, production of natural steroids by the adrenal glands is "turned off".
- At the end of taper (below 5 mg daily), must slow down more to allow adrenal glands to "wake up".
- Stopping high-dose steroids suddenly creates risk of adrenal insufficiency, which feels miserable(similar to the flu) and can be life threatening!
- Steroids have proven effective for treating MOG-AD attacks, but long-term use has significant side effects.
- Long term side effects may include: high blood pressure, unusually high blood sugar (which inpatients without diabetes usually resolves after treatment ends), unusual weight gain, bone loss, joint pain, irritability or other mood changes, puffy or "moon" face, acne, glaucoma, cataracts, facial hair growth, and slow growth in children.
- Some MOG-AD patients may experience steroid dependency where relapses occur when tapering dose goes below 10mg. These patients cannot come off steroids without a preventative medication.
- In some cases, as a last resort, medical professionals may use oral steroids as a preventative medication when other options do not control relapses, however, it is not considered to be a good option because of the associated long-term health risks.

ACUTE TREATMENT

PLEX (PLASMA EXCHANGE, PLASMAPHERESIS, THERAPEUTIC PLASMA EXCHANGE, TPE)

HOW IT WORKS

- Removes large amounts of unhealthy plasma from the blood via IV through a machine, and is exchanged with healthy plasma or a plasma substitute.
- Unhealthy plasma is discarded once the procedure is complete.
- A short-term method for removing harmful antibodies

DOSING & ADMINISTRATION

- Dosage: typically, 1-1.5 times the plasma volume per session or 39-55 mL of plasma per kg body weight.
- Administration: performed on alternating days for 5 to 7 treatments.
- Procedure takes 2-4 hours
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- A large IV catheter may be placed in the neck or chest and maintained until all treatments are complete.
- Less commonly, an IV is placed in the arm and removed after each session.
- Drink lots of water prior to treatment to help avoid lowering in blood pressure.

POTENTIAL SIDE EFFECTS

- Common: tiredness, a temporary decrease in the ability for the blood to clot, and lower blood pressure during the procedure which may cause dizziness, weakness or nausea.
- Serious: If a catheter is used, bleeding or infection may occur at the site, some patients may have an allergic reaction to donated plasma and blot clots can occur.

SPECIAL CONSIDERATIONS

- PLEX can be given concurrently with steroids but not IVIG.
- PLEX following IVIG will remove the IVIG from the systemic circulation.
- Sequencing with other therapies is important to consider.
- Tolerability of PLEX in pediatric patients may vary depending on age and clinical presentation.

ACUTE TREATMENTS

IVIG (INTRAVENOUS IMMUNOGLOBULIN)

HOW IT WORKS

- Plasma derived product containing antibodies from donors.
- Complex effect on immune system but net effect is to dampen overactivity and decrease production of harmful antibodies like MOG IgG
- Unlike most other treatments, does not weaken the immune system (and can actually provide more immune protection)

DOSING & ADMINISTRATION

- Dosage: first dose 2 g/kg ideal body weight; subsequent dosages: same or less (e.g. 1 g/kg).
- Dosage is based on ideal body weight because in SPECIAL CONSIDERATIONS some overweight patients may have serious side effects or overdose can occur.
- Administration: via IV for 3-5 days
- May be used as long-term therapy or bridge to other therapies
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- Your doctor may order pre-and post-fluids to keep you hydrated and to prevent blood clots.
- Other pre-meds can include diphenhydramine (Benadryl), acetaminophen (Tylenol) and anti-nausea medication.
- NSAID medicines like ibuprofen (Advil) can also be given.

POTENTIAL SIDE EFFECTS

- Common: headache, muscle or joint aches, and low grade fever.
- Serious: hives, tight feeling in your chest or wheezing, rise in blood pressure or heart rate, heart burn and aseptic meningitis.

SPECIAL CONSIDERATIONS

- To help prevent / minimize side effects a slow infusion rate may be used.
- Your doctor may also order steroids to help with possible side effects.
- Inform your doctor if you have heart disease or other risk factors for clotting as IVIG may increase this risk.
- PLEX following IVIG will remove the IVIG from the systemic circulation.

PREVENTATIVE TREATMENTS

IVIG (INTRAVENOUS IMMUNOGLOBULIN)

HOW IT WORKS

- Plasma-derived product containing antibodies.
- Triggers a flushing of the immune system, including the MOG antibodies.
- May help strengthen your immune system so that you can fight infections.
- Appears to prevent relapses particularly in children with multiple relapses in a year.

DOSING & ADMINISTRATION

- Dosage: first dose is 2 g/kg ideal body weight; subsequent doses: 1 g/kg.
- Dosage is based on ideal body weight because in some overweight patients serious side effects or overdose can occur.
- Administration: given via IV every 3-4 weeks.
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- Your doctor may order pre-and post-fluids to keep you hydrated and to prevent blood clots.
- Other pre-meds can include diphenhydramine (Benadryl), acetaminophen (Tylenol) and anti-nausea medication.
- NSAID medicines like Ibuprofen (Advil) can also be given

POTENTIAL SIDE EFFECTS

- Common: headache, muscle or joint aches, and low grade fever.
- Serious: hives, tight feeling in your chest or wheezing, rise in blood pressure or heart rate, heart burn and aseptic meningitis.

SPECIAL CONSIDERATIONS

- To help prevent/ minimize side effects a slow infusion rate may be used.
- Your doctor may also order steroids to help with possible side effects.
- Kidney function levels prior to infusion are monitored as acute kidney failure is possible.
- Inform your doctor if you have heart disease or other risk factors for clotting as IVIG may increase this risk.

PREVENTATIVE TREATMENTS

MYCOPHENOLATE MOFETIL (MMF, CELLCEPT, MYFORTIC)

HOW IT WORKS

- Immunosuppressant commonly used in transplant patients.
- Inhibits the growth of T and B lymphocytes

DOSING & ADMINISTRATION

- Dosage: adults 2000-3000 mg/day. Pediatric dosing is adjusted based on body surface area.
- Available in 250 mg capsules or 500 mg tablets or liquid suspension.
- Administration: orally twice a day, typically spaced 12 hours apart.
- Reaches its full effectiveness after 3–6 months.
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- Decide to take mycophenolate either with or without food, and take it the same way each time.
- Your doctor may order a drug level or lymphocyte count to ensure you to suppress your body's immune response are at the right dosage.
- Regular blood count and liver function monitoring is needed

POTENTIAL SIDE EFFECTS

- Common: digestive problems such as constipation, nausea, gas, vomiting and diarrhea, tremor, dizziness, drowsiness and trouble sleeping.
- Serious: unusual tiredness, fast/irregular heartbeat, easy bleeding/bruising, swelling of the feet or ankles, and low blood counts.

SPECIAL CONSIDERATIONS

- Digestive problems usually subside after 1 month of use.
- If you experience digestive problems on generic mycophenolate, your doctor may prescribe a brand name alternative.
- Suppresses your immune system and increases your infection risk.
- Some side effects such as stomach pain and fever may occur more often in children.

PREVENTATIVE TREATMENTS

RITUXIMAB (RITUXAN)

HOW IT WORKS

- Man-made antibody developed using DNA technology from human and mice genes.
- Belongs to the monoclonal antibody drug class and causes rapid B-cell depletion.

DOSING & ADMINISTRATION

- Dosage: typical starting dosing is 1000 mg x 2, 2 weeks apart or 375 mg/m² weekly x 4 weeks.
- Maintenance dosing is typically every 6 months.
- Administration: via IV typically two doses two weeks apart, repeated every 6 months.
- Some patients may need treatments more or less often based on B-cell regeneration as determined with blood monitoring.
- ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- Typically preferred to start in medical setting given risk of infusion reactions, but some patients can transition to home infusions.
- The entire infusion visit can take up to 6 hours; patient should have assistance with transportation home.
- Fever-reducing medications, antihistamines, and corticosteroids may be administered prior to infusion to decrease chance of side effects.

POTENTIAL SIDE EFFECTS

- Common: during the infusion potential side effects include fever, chills, hives, itching, nausea, fatigue, headache, and difficulty breathing. Serious:
- Long-term rituximab use may lower immunoglobulin levels which may require supplemental IVIG infusions; B cell depletion can increase infection risk.

SPECIAL CONSIDERATIONS

- Some hidden infections like tuberculosis or hepatitis B may emerge with treatment and need to be screened before starting therapy.
- Rituximab is not the preferred preventative treatment for all MOG AD patients as some patients have frequent relapses on it.

PREVENTATIVE TREATMENTS

AZATHIOPRINE (IMURAN)

HOW IT WORKS

- Immunosuppressant that weakens the immune system to prevent further damage to your central nervous system.

DOSING & ADMINISTRATION

- Dosage: Starting dose typically 1 mg/kg body weight (50-100 mg) daily. May increase up to 2.5 mg/kg.
- Administration: orally twice daily.
- Reaches its full effectiveness after 6-9 months.
 - ❖ Caution: Treatment dosage is presented as a typical guideline however your doctor will recommend the dosage that is right for your specific case. Please discuss your situation with your specialist who will work with you to create the best treatment plan for you.

WHAT TO EXPECT

- Taking this medication after meals may help lessen side effects.
- Your doctor will need to examine you and perform blood tests on a regular basis.

POTENTIAL SIDE EFFECTS

- Common: nausea or vomiting, children may feel tired or weak and have a lowered appetite.
- Serious: low levels of white blood cells, anemia, decreased blood platelets, and a higher risk of developing skin cancer and lymphoma.

SPECIAL CONSIDERATIONS

- Azathioprine will weaken your immune system and increase your infection risk.
- Some people have low levels of an enzyme called TPMT, which can lead to toxic azathioprine levels; your doctor may check this before prescribing it.

FOOD FOR THOUGHT ON MEDICATION CHOICE

- Since medication and dosage is uniquely matched for an individual, we strongly encourage you to discuss your situation with your specialist who will work with you to create the best treatment plan for you.
- Many of these medications are used in combinations to address subtle differences in presentation of the disease.
- Medical professionals will use a combination of medications and therapies to address each individual's age, symptoms and side-effects experienced in addition to considering the efficacy of the treatment, the impact on lifestyle as well as the patient's financial situation.
- There have been a number of studies done to determine if a single medication or combination of medications are the most effective way to treat MOG-AD.
- Researchers are continuing to explore these concepts as there is currently no one size-fits-all solution due to the complexity of MOG-AD.
- We will continue to provide the community updates to medical research for MOG-AD and we would like to seek your participation in surveys on your treatment experience.

FINAL THOUGHTS

- The medical community is learning about this disease in real time, in fact no medication is approved by the FDA for treatment of MOG-AD.
- Until recently, acute and preventative treatments have mirrored the treatments used in other neuroimmune diseases, for example NMOSD.
- No medication is 100% successful, what works for one person may not work for another.
- Every medication has a risk of side effects, talk to your doctor about which treatment is right for you.

We want to hear from you;

Let your voice be HEARD!

Please click on the link below to participate in a confidential 5-minute survey on you or your loved one's MOG-AD treatment experiences. This is a collaborative

effort between The MOG Project, the Siegel Rare Neuroimmune Association and The Sumaira Foundation for NMO. Results of the survey will be shared in the coming months.

Please click the link to access the survey

www.research.net/r/MOGtreatment

Survey participants will be entered into a drawing for FREE SWAG courtesy of The MOG Project and The Sumaira Foundation for NMO!

This series is brought to you by

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