IMMUNE-MEDIATED NECROTIZING MYOPATHY (IMNM)

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What is IMNM?

Immune-Mediated Necrotizing Myopathy (IMNM), also referred to as Necrotizing Autoimmune Myopathy (NAM), is one of the Idiopathic Inflammatory Myopathies (IIM) and is a rare autoimmune muscle disease. The cause in many cases is unknown, and there is no cure.

IMNM is divided into three subgroups, based on autoantibodies. Research into autoantibodies is still emerging and ongoing. The three subgroups are:

- **Anti-HMGCR Myopathy.** Often associated with the use of cholesterol-lowering drugs known as statins. However, discontinuing the statin medication does not necessarily relieve the patient's symptoms, as there is an autoimmune process involved. Younger patients who have never used statins may also test positive for this autoantibody.
- **Anti-SRP Myopathy.** Often associated with severe and sudden onset of muscle weakness. Some people experience cardiac involvement.
- **Antibody-Negative IMNM.** Not associated with a known myositis autoantibody. However, muscle biopsy findings and highly elevated CK levels help to diagnose this subtype. Antibody-Negative IMNM patients may have an increased risk of cancer.

What are the symptoms of IMNM?

IMNM includes weakness of the muscles closest to the body's core, such as hips, neck, shoulders, upper arms, and thighs, and can progress over weeks or months. In addition to weakness, people with IMNM experience muscle pain, fatigue, and atrophy, which can lead to disability. In younger people, IMNM can be chronically progressive and mimic adult-onset muscular dystrophy.

Other symptoms can include:

- Debilitating fatigue, trouble swallowing, and muscle pain.
- Damage to other organs of the body, such as the heart and lungs.

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How is IMNM diagnosed?

Diagnosing IMNM can be difficult. The process may include exams and several tests and may vary depending on symptoms:

- First, doctors usually get a patient history and conduct a physical exam.
- Then, they may order blood tests to check for myositis-specific antibodies, muscle enzymes (CK), and other inflammatory, autoimmune, and cancer markers. IMNM can be characterized by remarkably high CK levels.
- Often, diagnosis is confirmed after an MRI, EMG, nerve conduction test, and/or muscle biopsy.

How is IMNM managed?

There are a variety of off-label medications that can be used to treat IMNM. Using assistive devices can also help manage symptoms. Most people with IMNM manage with a combination of the following:

- **Medications.** IMNM treatments often start with oral or IV steroids. Off-label use of other medications may be successful, including immunosuppressive agents, chemotherapy medications, and infusion therapies, like IVIG, and monoclonal antibodies, like rituximab.
- **Assistive devices.** A cane, walker, rollator, or wheelchair can help with balance and weakness. Assistive devices can be used for short periods, such as during flares, or for long-term muscle weakness or damage.
- **Movement.** Physical therapy and exercise are usually recommended for all myositis patients. Talk with your doctor before starting any exercise routine.

Where can I find more information?

Myositis Support and Understanding has a robust website full of resources including information about IIM, how to manage these difficult conditions, and where to find support. Go to **www.understandingmyositis.org** or use this QR code to learn more!