Necrotizing Autoimmune Myopathy (NAM) In Focus

- Necrotizing Autoimmune Myopathy (NAM), also known as Immune-Mediated Necrotizing Myopathy (IMNM), is a very rare form of the Idiopathic Inflammatory Myopathies (IIM) and is a systemic autoimmune muscle disease. There are several potential causes, but there is no cure.
- Typical findings of NAM include severe muscle weakness, highly elevated CK/CPK levels (muscle enzymes that can indicate muscle damage), and muscle pain.
- NAM can appear much like Polymyositis (PM), another of the Inflammatory Myopathies, causing symmetrical weakness (same on both sides) in muscles closest to the body's core (proximal) such as hips, neck, shoulders, upper arms, and thighs, and can develop over days, weeks, or months. Muscle weakness can cause difficulty getting out of a chair, raising arms over the head, combing hair, lifting, brushing teeth, walking, and other activities.
- NAM may be associated with certain autoantibodies such as anti-SRP and anti-HMGCR, anti-mitochondrial antibodies, and even more rarely, anti-Jo-1, and can also be associated with cancer, viral infections, or other connective tissue diseases such as scleroderma.
- In some cases, NAM is associated with the use of cholesterol-lowering drugs known as statins; however, discontinuing the statin medication does not relieve the patient's symptoms, as there is an autoimmune process involved.
- Other symptoms of NAM may include debilitating fatigue, weight loss, trouble swallowing (which can cause choking and aspiration), difficulty breathing, skin rash, and muscle pain.
- Diagnosing NAM can be difficult and may take months or years. Patient history, physical exam, Myositis-Specific antibodies (MSA), Myositis-Associated antibodies (MAA), other blood tests (muscle enzymes, inflammatory, autoimmune, and cancer markers, and other antibodies), MRI, EMG, nerve conduction studies, and a muscle biopsy can assist in making a diagnosis. Muscle biopsy findings for NAM will likely shows little-to-no muscle inflammation, which can help to differentiate NAM from other forms of inflammatory myopathies.
- Treatment for NAM is often steroids, which are not recommended for long-term use, combined with Immunoglobulin (Ig) therapy. Other medications may be tried and used successfully to treat NAM and may include immunosuppressive agents, chemotherapy medications, and monoclonal antibody therapy (rituximab). These medications present patients with risks of harsh side effects and a weakened immune system.
- Physical therapy and exercise are recommended for NAM patients and all myositis patients.
- NAM patients may require the use of assistive devices for mobility, such as a cane, walker, rollator, or wheelchair, either for short periods, such as during flares or for long-term muscle weakness and damage.

Patients with NAM may look healthy (invisible illness) and appear able-bodied, but are often struggling internally. Others may use oxygen and require assistive devices for mobility. Each patient is very different.

With all the difficulties in the diagnostic process and living with this disease, the journey takes a toll on patients and families alike. Look closer and put #MyositisInFocus and learn more about Necrotizing Autoimmune Myopathy at www.UnderstandingMyositis.org/nam