



**Myositis** (my-oh-sy-tis) is a rare, progressive muscle disease that causes inflammation of the muscles and associated tissues such as the blood vessels that supply the muscles. This inflammation can result in muscle weakness, pain, fatigue, skin rashes, lung disease, difficulty swallowing, and a higher-than-normal incidence of cancer. Our focus is on the Idiopathic Inflammatory Myopathies.

Polymyositis (PM) and Dermatomyositis (DM) are considered autoimmune diseases, but there is a lack of agreement whether Inclusion Body Myositis (IBM) is actually considered autoimmune. As with all autoimmune diseases, there is no known cause, but it is thought that a genetic predisposition is triggered by a virus or an environmental stimuli. For complete information, [visit our website](#).

**Myositis is considered a rare, chronic autoimmune disease for which there is no cure**

**Symptoms:** Both PM and DM have overlapping symptoms, but not everyone will have all symptoms.

**Polymyositis (PM) & Dermatomyositis (DM):**

- Weakness of muscles closest to the body's core like quadriceps, hip flexors, upper arms, neck, and shoulders
- Difficulty using stairs, rising from a seated position, walking, especially on uneven surfaces, and trouble raising arms over the head.
- Muscle pain and life-altering fatigue
- Weight loss and low-grade fever
- Irregular heartbeat
- Shortness of breath
- Difficulty swallowing and weak vocal chords
- Lung disease

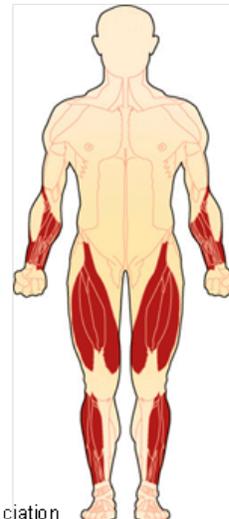
**Muscles commonly affected**



**Inclusion Body Myositis (IBM):**

- Weakness of muscles farther away from the body's core such as forearms, wrists, and fingers but can also include quadriceps.
- Difficulty using stairs
- Spontaneous buckling of the knees causing falls
- Weakness in the ankles and tendons causing tripping and falling due to "foot drop"
- Difficulty using fingers like pinching, buttoning, making a fist, and using a computer
- Diminished deep tendon reflexes
- Difficulty swallowing which may necessitate use of a feeding tube

**Muscles commonly affected**



Illustrations courtesy of the Muscular Dystrophy Association

**Dermatomyositis Skin Involvement:** Skin involvement may precede the muscle symptoms above for months or years, or muscle involvement may never be a concern (Amyopathic Dermatomyositis). Skin rashes and discolorations on sun-exposed areas such as cheeks, nose, shoulders ("shawl" rash), upper chest ("V-Sign"), and elbows are often present and may be itchy and intense enough to disturb sleep. Hands may have Gottron's sign and/or Mechanics Hands. A Heliotrope-colored rash on the upper eyelids may also be present.

## TREATMENT for MYOSITIS

There is no cure for any form of Myositis, however some patients with PM and DM may respond to one or a combination of drugs designed to suppress the immune system such as: corticosteroids (Prednisone, Solumedrol, Acthar Gel), chemotherapy (Rituxan), Disease Modifying Anti-Rheumatic Drugs (DMARDS) such as Imuran, CellCept, Methotrexate, and Plaquenil, infused blood products (IVIG), and Biologic Response Modifiers (BRM's) such as Remicade and Enbrel. Often patients must weigh the benefits and risks as many medications have unfortunate side effects and finding the right combination for each patient can be challenging. Some have also found that "natural living" has improved their quality of life.

## FATIGUE and CHRONIC PAIN

Immobilizing fatigue is often present in many autoimmune diseases, and Myositis is no exception. Pain associated with Myositis is becoming more accepted and understood by physicians, but many medical schools taught that pain was not a symptom thus creating frustration for both patients and physicians. There are still healthcare providers who do not acknowledge Myositis can be accompanied by pain. This is changing as physicians learn more about Myositis and listen to their patients. It is estimated that 40% of Myositis patients live with pain.

## INVISIBLE DISEASE

For some, getting others to understand the weakness, fatigue, pain, and the inability to keep promises to loved ones, due to life with Myositis, can be difficult. Patients may look healthy on the outside while on the inside, their bodies are "screaming." Learning effective coping methods, educating friends and family members, and forming a support network are all great ways to help, although others may never truly understand unless they have lived with a similar ailment.

## MSU SUPPORTS MYOSITIS PATIENTS AND CAREGIVERS

- Myositis Support and Understanding (MSU) is a growing 501(c)(3) nonprofit organization founded on the idea that even though patients are diverse and far-stretched across the globe, they can come together to share information on the effects, commonalities, and complexities of Myositis.
- Through individual trial and error, similar experiences, and empathy for each other, we are building a supportive and informational network of camaraderie in which people can better understand their disease, effectively advocate for themselves, and realize they don't have to be alone in their struggles and that they can live a happy life.
- We hope that our members will feel informed and empowered. At the end of each day, if even one member can say, "I'm relieved to know I am not alone and that my experiences are real," we will count ourselves a success!

## OUR MISSION:

Myositis Support and Understanding (MSU) is dedicated to improving the lives of Myositis patients through public policy, self-advocacy programs, need-based financial assistance for medical-related expenses, and to provide support and education to patients, caregivers, healthcare providers, the general public, and legislators about Myositis. MSU will foster direct involvement with other Myositis organizations to help promote treatment innovation and research with our collective eyes on a cure and provide financial support to organizations that share similar visions.

*\* The information contained in this document is not intended to be medical advice. Be sure to consult with your physician and other healthcare providers before making any healthcare decisions.*

**Visit us online at [UnderstandingMyositis.org](http://UnderstandingMyositis.org)**

