



## THE MYOSITIS ASSOCIATION

The Myositis Association (TMA) is a non-profit, voluntary health agency dedicated to improving the lives of people affected by myositis. Formed in 1993, TMA has grown from 16 patients, who helped form the organization, to more than 6,000 members who have been served by TMA.

TMA is governed by a volunteer Board of Directors that includes patients, family members and interested professionals, bringing diverse strengths and perspectives to the organization.

Through member newsletters, publications, support groups, research and advocacy, TMA helps those who have myositis today and works to prevent any others from having to experience myositis in the future.

The mission of The Myositis Association is to find a cure for inflammatory and related myopathies, while serving those affected by these diseases.



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“Myositis” describes inflammation or swelling of the muscle tissue. General muscle inflammation can occur after exercising or taking certain medication, or it can be from one of the chronic inflammatory muscle disorders. Dermatomyositis (DM), polymyositis (PM), inclusion-body myositis (IBM), and juvenile forms of myositis (JM) are all inflammatory myopathies, or diseases where there is inflammation and loss of muscle. Depending on the type of myositis, the first signs of myositis may include general tiredness, trouble standing from a seated position, difficulty climbing stairs, and weak grasping of objects.

The underlying causes of DM, PM, IBM and JM are not known, but some doctors believe there is an environmental exposure (perhaps to an infection or sunlight) that triggers the disease in someone who has certain specific but not yet fully defined genes or gene sequences that predispose him or her. Inflammatory myopathies are classified as autoimmune diseases, meaning the body's immune system, which normally fights infections and viruses, does not stop fighting once the infection or virus is gone. The immune system is misdirected and attacks the body's own normal, healthy tissue. Inflammatory myopathies are rare diseases and combined affect an estimated 50,000 people in the U.S.

### DERMATOMYOSITIS

Dermatomyositis (DM) affects people of any age or sex but is more common in women than men. DM is the easiest type of myositis to diagnose because it typically has a visible skin rash caused by inflammation of blood vessels under the skin. The DM rash looks patchy and reddish or purple, and is found on the eyelids, elbows, knees and knuckles. Additional rashes may occur on the cheeks, nose, back, and upper chest. Some people also have hardened bumps under the skin, called calcinosis. Patients usually experience gradual muscle weakness and sometimes pain, and they often report the rash well before the muscle weakness. Three sub-types of DM are amyopathic DM, where the skin is affected but muscles are not involved; cancer-associated DM, where cancer and dermatomyositis are diagnosed within two to three years of one another; and overlap, where DM is associated with other autoimmune diseases.

### POLYMYOSITIS

Polymyositis (PM) is found more frequently in adults than children. More women than men have PM. Patients experience muscle weakness gradually over weeks or months, typically beginning with muscles closest to and within the trunk of the body, such as neck, hip, back and shoulder muscles, and affecting both sides of the body equally. Some patients also have weakness in their hands and fingers. PM patients generally do not have skin rashes. Some PM patients have trouble swallowing (dysphagia), difficulty breathing (often associated with interstitial lung disease) and muscle pain. PM may be associated with a malignancy or with other autoimmune diseases (overlap).

### INCLUSION-BODY MYOSITIS

Inclusion-body myositis (IBM) is found in more men than women and is rarely seen in people less than 50 years old. IBM progresses more slowly than the other types of myositis, as weakness happens gradually over months or years. Some of the first signs of IBM are falling, difficulty standing from a seated position, and weakening grip. Muscles most often affected are those at the front of the thighs, hips, foot-elevators, fingers, wrists, upper arms, shoulders, neck, and back. Many IBM patients notice shrinking, or atrophy, in the arms and thighs as the muscles become weaker. Trouble swallowing (dysphagia) is a common problem for IBM patients. Weakness of facial muscles is sometimes seen.

### JUVENILE MYOSITIS

Juvenile forms of myositis (JM) occur in children younger than 18 and affect more girls than boys. Juvenile dermatomyositis (JDM) is the most common form, affecting an estimated 3,000 to 5,000 children in the United States. Polymyositis in children (JPM) occurs in approximately 10% of children with JM. Signs of JM include the characteristic skin rashes (i.e. a visible, reddish-purple rash over the eyelids or over joints), trouble climbing or lifting the head, weak voice (dysphonia), or problems swallowing (dysphagia). The muscles most often affected are those closest to the center of the body – neck, stomach, upper arms, and legs. About half of the children with JM report pain in their muscles. Some children have calcinosis (hardened lumps under the skin) or contractures (when the muscle shortens and causes the joint to stay bent). Children may have one or more other autoimmune diseases along with myositis (overlap myositis).