

THE MYOSITIS ASSOCIATION - AUSTRALIA INCORPORATED

Keeping in Touch Group

The Myositis Association Australia Inc (TMAA) is a non-profit, voluntary health agency dedicated to improving the lives of people affected by Myositis. Formed in 2003 in Australia as part of the Myositis Association of America, it has grown from 12 patients, who helped form the organization, to more than 150 members, but the actual number of people in Australia with Myositis is unknown.

TMAA conducts a Myositis Awareness Week in Australia during the third week in September to try and raise the profile of Myositis within the community and medical profession.

TMAA is run by a volunteer Committee that includes patients and interested professionals, bringing diverse strengths and perspectives to the organization.

Through member newsletters, publications, support groups, research and advocacy, TMAA 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-
Australia Inc***

***is to find a cure for inflammatory and
related myopathies, while serving those
affected by these diseases.***

THE MYOSITIS ASSOCIATION-AUSTRALIA INC

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*Is working to help Myositis pa-
tients build up their diseased
muscle tissue by raising
awareness of*

POLYMYOSITIS

WHAT IS POLYMYOSITIS (PM)?

“Myositis” describes inflammation or swelling of the muscle tissue. General muscle inflammation can occur after exercise or taking certain medication, or it can be from a chronic inflammatory muscle disorder like polymyositis (PM). Although the underlying cause of the PM inflammation is unknown, some doctors believe there is an environmental exposure (perhaps to an infection or medicine) that triggers the disease in someone who has certain specific but not yet fully defined genes or gene sequences that predispose him or her.

PM is found mostly in people over the age of 15 and affects women more commonly than men. Some of the first signs of PM are:

- General tiredness;
- Sometimes discomfort or pain in affected muscles;
- Difficulty climbing stairs, arising from a seated position, or reaching up above the shoulders;
- Difficulty swallowing or, rarely, shortness of breath.

Two sub-types of PM are overlap myositis, when the patient has at least one other autoimmune disease (such as lupus, scleroderma, or arthritis) along with myositis; and cancer-associated myositis, when the diagnoses of myositis and cancer occur within two to three years of one another.

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 through inflammation.

WHAT ARE THE SYMPTOMS OF PM?

Muscle weakness that is progressive, usually developing over a period of weeks or months, is the main symptom, and some people experience muscle pain. The weakness is usually symmetrical, affecting both sides of the body about equally, and is typically found in hip, thigh, upper arm, shoulder, neck and back muscles. Hand and finger muscles are also sometimes involved. Some people have trouble swallowing (dysphagia), difficulty breathing (often associated with interstitial lung disease), and other complications.

HOW DO DOCTORS TEST FOR PM?

Your doctor may first ask questions about your health in general, including your health history and when you first saw signs of muscle weakness. He or she will then do a physical exam to assess muscle strength and will typically ask the hospital's lab to run one or more of the following tests:

- Blood tests for muscle enzymes (including CK and aldolase tests) and other blood factors
- Muscle biopsy
- Electromyogram (EMG) and nerve conduction velocities (NCVs)
- Magnetic resonance imaging (MRI) of the muscles

Your doctor may order other tests to rule out other diseases or conditions. If you have questions about any test, be sure to talk with your doctor or lab technicians, or visit TMA's web site at www.myositis.org.

HOW IS PM TREATED?

Medicines used to treat PM aim to slow the immune system and stop the inflammatory attack on the muscle and other body systems. blood

Prednisolone, a corticosteroid medicine, is often effective as a first-line treatment in controlling the inflammation and increasing muscle strength; however, there are possible negative side effects, including weight gain from fluid retention, osteoporosis, cataracts, mood swings, high pressure, and diabetes. (Diabetes is an increased risk if the patient has a family history of adult-onset type-2 diabetes, or is overweight.) You and your physician should carefully consider the potential benefits and risks of this and other medicines.

Your doctor may prescribe other immunosuppressant medicines – medicines that also slow the body's immune system and inflammatory response – to be used in place of or in addition to a corticosteroid. When used in combination with a corticosteroid, the additional immunosuppressant allows patients to use a lower dose of the corticosteroid, thereby lessening the corticosteroid's undesirable side effects. Immunosuppressants include azathioprine and methotrexate. Cyclosporine and cyclophosphamide may be used and are especially applicable if there is lung involvement, but they require extra caution.

Intravenous immunoglobulin (IVIg) has been used with some success in treating difficult cases of PM. While you are on any of these drugs, your doctor will monitor your blood tests closely. Other immunosuppressants are being studied, and there is considerable work currently underway to develop new and more effective treatments.

Your doctor will talk to you about complementary, non-medical treatment like physical and occupational therapy, and exercise appropriate to the individual patient.