

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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DISCLAIMER

***This brochure for Juvenile Dermatomyositis
IS A GUIDE ONLY***

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*is working to help My-
ositis patients build up
their diseased muscle
tissue by raising
awareness of
JUVENILE
DERMATOMYOSITIS*

WHAT IS JUVENILE MYOSITIS?(JM)

“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 a chronic inflammatory muscle disorder like juvenile myositis (JM). There are several other terms used – juvenile idiopathic inflammatory myopathies (JIIM), a medical term; or juvenile dermatomyositis (JDM) and juvenile polymyositis (JPM), more specific to the illness subtypes. Although the underlying causes of JM inflammation are not known, 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. JM begins in childhood before the age of 18 and affects more girls than boys. Some of the first signs are:

- A visible, reddish-purple rash over the eyelids or over joints, such as knuckles, elbows or knees;
- General tiredness;
- Moodiness or crankiness;
- Trouble climbing stairs or standing from a seated position; trouble dressing;
- Difficulty reaching up, like to shampoo or comb hair.

With JDM, skin and muscles are affected, causing characteristic skin rashes. In JPM, there is no skin involvement, but many muscles are affected. Two sub-types of juvenile myositis are: overlap myositis, when the child has at least one other autoimmune disease (like lupus, scleroderma, diabetes, celiac disease, or arthritis) along with myositis; and amyopathic myositis, or DM sine myositis, where the skin is affected but muscles are not involved.

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 JM?

The skin rash of JDM is caused by inflammation of the blood vessels under the skin. The rash may be painful and/or itchy, or may not cause any discomfort. Two rashes characteristic of JDM are Gottron's papules, or bumps found over the knuckles, elbows and knees; and the heliotrope rash, or a purplish rash around the eyes, like a flower.

In both JDM and JPM, patients usually experience muscle weakness gradually, developing over a period of weeks or months, and some patients experience muscle pain. Children may have trouble standing up, climbing steps, or lifting their heads. The muscles most often affected are those closest to the center of the body – neck, stomach, upper arms, and legs. Children may have other, less common complications as well – calcinosis, trouble swallowing (dysphagia), hoarse voice (dysphonia), stomach problems, or arthritis.

HOW DO DOCTORS TEST FOR JM?

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

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

Your child's 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 technician, or visit TMA's web site at www.myositis.org.

HOW IS JM TREATED?

Medicines used to treat JM aim to slow the immune system and stop the inflammatory attack on the muscle, skin and other body systems. High-dose Prednisolone, a corticosteroid medicine, is often effective as a first-line treatment in controlling the inflammation and increasing muscle strength. The doctor will closely monitor your child for possible negative side effects, including stomach upset, weight gain, brittle bones, cataracts, and moodiness. You and your child's 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 corticosteroids. 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. Immunosuppressant medicines include methotrexate, intravenous immunoglobulin (IVIg), cyclosporine, and azathioprine. These, too, can have adverse effects. Long-term effects of some medications are still unknown, and they may require extra caution. The doctor will monitor your child's blood tests closely. Other immunosuppressants are being studied, and there is considerable work currently underway to develop new and more effective treatments. Sometimes physicians prescribe topical forms of corticosteroids or other medicines to treat the skin symptoms. Your doctor will talk to you about complementary, non-medical treatment like physical and occupational therapy, appropriate exercise, and especially sun protection, since in many cases exposure to sunlight exacerbates the disease.