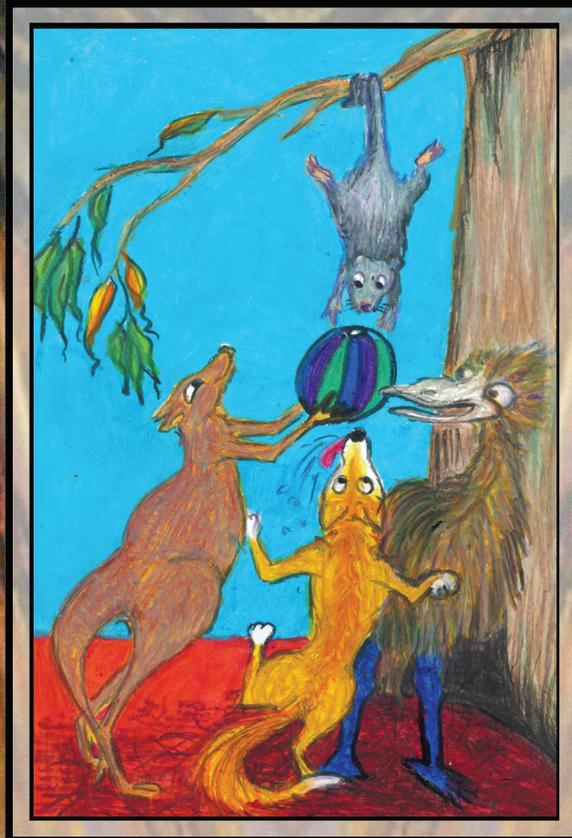
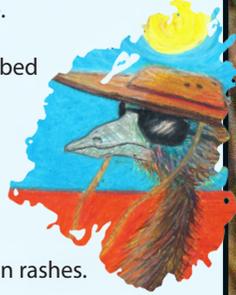


Things that may be helpful

Juvenile Dermatomyositis can be well managed, but it may be helpful to:

- ➡ Learn as much as you can about your illness.
- ➡ See your doctors regularly to monitor treatments & help you live a healthier life.
- ➡ Always take the drugs prescribed by your doctor.
- ➡ Put on sun screen to protect the skin from sun damage. Always wear a hat.
- ➡ Use lotions to help soothe skin rashes.
- ➡ Do physical & occupational therapy exercises to help muscles work better & get stronger.
- ➡ Exercise is good for you as it strengthens muscles & keeps joints flexible. If you are feeling unwell you should reduce you exercise until you feel better.
- ➡ Tiredness is common so resting is good. Learn to timetable rest times after active times.
- ➡ Pay attention to your body & slow down especially when you are not feeling well.
- ➡ Consider speech therapy to help with swallowing problems.
- ➡ Seek advice from a dietician to learn about foods that can help you & different ways to prepare foods.

- ➡ Include a variety of foods in your diet.
- ➡ Don't eat too many foods that contain high levels of sugars, salt & fats.
- ➡ Drink adequate fluids, in particular water.



WHERE CAN I GET HELP?

Autoimmune Resource & Research Centre

Telephone: 02 49214095

email: arrc@autoimmune.org.au

web: www.autoimmune.org.au

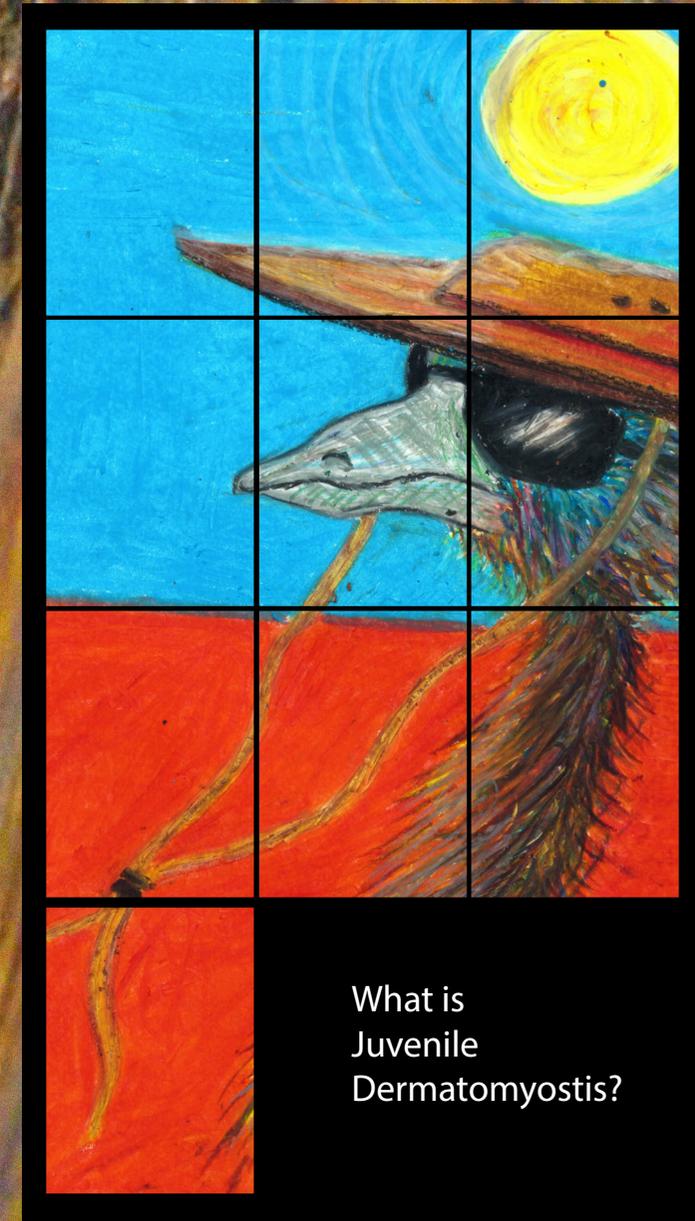
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Morgan Williams, Griphon Graphics © 2019

Juvenile Dermatomyositis



What is
Juvenile
Dermatomyositis?

What is juvenile dermatomyositis?

It is a condition in children that causes skin rash (dermato-) muscle inflammation & weakness (-myositis). Blood vessels in the skin may also be affected.

What causes juvenile dermatomyositis?

We don't know what causes juvenile dermatomyositis but we do know that it involves the immune system. Our body uses the immune system to protect itself from harmful things such as bacteria & viruses (bugs). We are not sure why some children have an immune system that does not work properly but we do know that when some people get sick it is caused by the system being over active & causing harm to itself. This is called autoimmune illness. Juvenile dermatomyositis is one of these.

There is nothing you could have done to stop yourself getting the condition. We also know that you cannot catch the condition from other people or give it to them.

What are the signs and symptoms?

Symptoms often appear slowly with the most common signs & symptoms being:

- ➡ Skin rash which is violet coloured or dusky red. The rash is most likely on the face, eyelids, around nails, elbows, knuckles, knees, chest & back. The rash can be patchy & have bluish-purple patches.
- ➡ Muscle weakness in the hips, thighs, shoulders, neck & upper arms. This often causes falls & makes it hard to get dressed or brush your hair for example.
- ➡ Muscle pain or soreness.
- ➡ Fever (a raised body temperature).
- ➡ Tiredness & fatigue.



- ➡ Loss of weight & poor appetite.
- ➡ Problems swallowing.
- ➡ Hardened lumps under the skin.
- ➡ Problems with the gut & lungs due to weakened muscle.



Fever

Problems swallowing

Tiredness

Loss of balance

Poor appetite

Hard lumps under skin

Sore joints

Loss of weight

Skin rash

Muscle Pain

Muscle weakness

Blue-purple skin patches

Tummy & lung problems

How is it diagnosed?

For most children, the condition can be diagnosed after episodes of repeated fever with tiredness, muscle weakness & rash. However not everyone has the rash at the start. A physical examination & patient history will help but other tests will be needed to make the diagnosis. The doctor will order tests that may include:



- ➡ Blood tests to look for inflammation & antibodies in the blood.
- ➡ An MRI (a type of x-ray) to look closely at muscles, organs & other tissues within the body.
- ➡ A muscle biopsy, which is a procedure where a small bit of muscle is removed & examined under a microscope.
- ➡ An electromyograph (EMG) which is a test for measuring electrical signals in your muscles. These signals are the messages between your brain & muscle that tell the muscle to move. This test can tell if muscles & tissues are damaged.

How is it treated?

There are many treatments used. None of these can cure the condition but can help you to feel better. Everybody has different symptoms so your treatment will be based on your symptoms & problems. Your doctor can explain which ones will best help you.



Treatments often include taking medications (drugs). The most commonly used drugs are:

- ➡ Prednisolone treats muscle inflammation
- Methotrexate suppresses the immune system.

These will be given to you in higher doses when you are sick & slowly reduced over time. You may also need to take higher doses if you have a time when your symptoms get worse. There are also many other drugs that are useful in treating specific symptoms. Your doctor will talk to you about these if they are needed.

For some children the condition does not last for very long while others have it for many years. Juvenile Dermatomyositis can be mild in some children & quite severe in others. Treatments can change over time & will only stop when doctors are sure you are free of symptoms of the condition.