



**Paediatric Systemic Lupus Erythematosus (SLE)
Australian Paediatric Surveillance Unit
Public Information Sheet**

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Lupus is a disease that can affect children or adults and has the potential to affect nearly every system in the body. It is an "autoimmune" disease. Usually the immune system is a surveillance system that allows us to detect and destroy foreign objects such as bacteria or viruses. However when a disease is 'autoimmune,' it means that the immune system starts to attack objects that are not foreign, but 'self'. This process leads to inflammation and sometimes serious damage to cells and organs.

It is not known exactly what causes lupus but there are potential triggers including:

- Genetic makeup
- UV radiation (including sunlight)
- Hormones (lupus is more common in females)
- Pregnancy
- Some medications

The symptoms of lupus are extremely variable as it may affect different parts of the body in different people. Symptoms may be general such as fatigue, fever and weight loss, or specific depending on the organ involved. Skin symptoms with rash or photosensitivity and joint swelling and/or pain are very common.

The diagnosis is not straightforward and involves assessment of possible organs involved and blood and urine tests. A thorough physical examination is required. Sometimes it may take a period of time to make the diagnosis. A skin or kidney biopsy may be needed.

There is no cure for lupus but it can be effectively managed with medications that target inflammation or the immune system. These may include NSAID's (non-steroidal anti-inflammatories), hydroxychloroquine or prednisone. More powerful suppressors of the immune system such as azathioprine, mycophenolate, cyclophosphamide or rarely rituximab may be necessary. Many newer ways of treating lupus and different ways to combine medications are the current subject of extensive research in lupus.

The outlook is variable depending on how the lupus affects the individual but, for those with milder forms of the disease, a normal life span can be expected. Lupus is a disease of flare-ups and remissions, so maintaining a healthy lifestyle, identifying risk factors for relapse, and maintaining an overall positive attitude and a good relationship with your medical professionals is vital to successfully managing lupus.

We are conducting a national surveillance study through the Australian Paediatric Surveillance Unit (APSU) to learn more about lupus in children and to provide the first national dataset on children with lupus. In particular we will describe the number of children with new diagnoses of lupus, and describe their geographical distribution and ethnic background. This study will also describe the types and severity of signs and symptoms, the way lupus is treated in Australia and 1 year outcomes for the children. This information will feed into the development of new diagnostic and treatment guidelines for health professionals.

For more information on lupus please see the following websites:

Lupus Association of NSW <http://www.lupusnsw.org.au/lwlupus.html>
Health Insite, Department of Health and Ageing <http://www.healthinsite.gov.au/topics/Lupus>
National Institutes of Health (USA) <http://health.nih.gov/topic/Lupus>
Lupus Foundation of America <http://www.lupus.org/newsite/index.html>