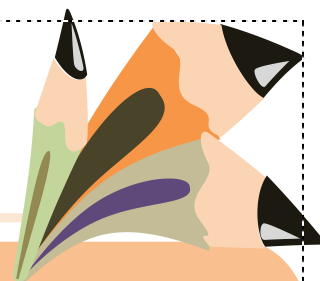


Childhood Lupus

A Guide for Patients & their Families



WHAT EXACTLY IS LUPUS?

Lupus is a chronic, autoimmune disease that can affect various parts of the body including the skin, joints, blood, and kidneys.

Chronic means that the signs and symptoms tend to last for a long time, longer than six weeks and often for many years.

In lupus, something goes wrong with your immune system, which is the part of the body that fights off “foreign invaders” like viruses, bacteria, and germs.

Normally, our immune system produces proteins called antibodies that protect the body from these foreign bacteria and viruses. Autoimmune means that your immune system cannot tell the difference between these foreign invaders and your body’s healthy tissues. The body begins to create autoantibodies (“auto” means “self”) which attack and destroy your body’s healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body.

Lupus is also a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better). With good medical care, most people with lupus can lead a full life. Lupus is not contagious and you cannot “catch” lupus or “give” lupus to someone.

HOW MANY PEOPLE HAVE LUPUS?

Research estimates that at least 1.5 million Americans have lupus. Between 5,000 and 10,000 children in the US are believed to have lupus.

SYMPTOMS OF LUPUS

The most common symptoms of lupus:

- extreme fatigue (tiredness)
- headaches
- butterfly-shaped malar rash across cheeks/nose
- sun or light sensitivity (photosensitivity)
- painful or swollen joints
- fever
- swelling (edema) in feet, legs, hands, and/or eyes
- pain in chest on deep breathing (pleurisy)
- anemia (low numbers of red blood cells or hemoglobin, or low total blood volume)
- abnormal blood clotting
- mouth or nose ulcers
- fingers turning white and/or blue when cold

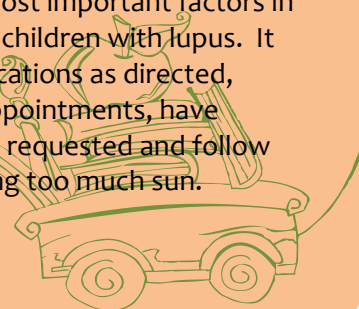
DIAGNOSING LUPUS

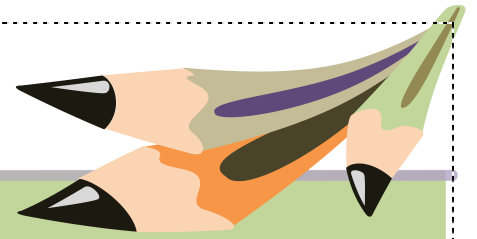
Lupus is a highly variable disease, where some children have obvious disease symptoms like fever, rash and kidney involvement and others simply feel tired or achy. Most physicians rely on the American College of Rheumatology criteria for the diagnosis of definite lupus.

Once the diagnosis is made, parents are concerned about what will happen to their child. While lupus can be a severe and life-threatening disease, many children with lupus will do very well when treated with medications.

FOLLOWING DOCTOR’S ORDERS

Compliance with physician instructions has been shown to be one of the most important factors in determining outcome for children with lupus. It is important to take medications as directed, keep scheduled doctor appointments, have blood or urine tests when requested and follow instructions about avoiding too much sun.





WHAT CAUSES LUPUS?

GENES

No gene or group of genes has been proven to cause lupus. Lupus does, however, appear in certain families, and when one of 2 identical twins has lupus, there is an increased chance that the other twin will also develop the disease. These findings and others strongly suggest genes are involved in the development of lupus.

Additionally, certain ethnic groups especially African Americans are at a greater risk of developing lupus, which may be related to genes they have in common.

ENVIRONMENT

When a person's genes may increase the chance that he or she will develop lupus, it takes some kind of environmental trigger to set off the illness and bring on a flare. Some examples are ultraviolet rays from the sun, a cold or viral illness, an infection, an injury, or stress. However, many people cannot remember or identify a specific environmental factor that occurred before they were diagnosed with lupus.

COULD OTHERS IN MY FAMILY DEVELOP LUPUS?

Studies have shown that close relatives of adults and children with lupus are more likely to develop lupus than are individuals selected randomly in the general population. However, the risk is still very small (about 1 in 50). If one of your other children has symptoms which make you think they might have lupus, have them evaluated by your physician.

Remember, a positive ANA does not make the diagnosis of lupus. In the absence of symptoms, it is appropriate to just carefully follow an ANA-positive child.

Information adapted from materials provided by the Lupus Foundation of America.



LUPUS WORD SEARCH!



AUTOIMMUNE	ANA	FATIGUE
JOINTS	FEVER	LUPUS
SWELLING	MALAR	ULCERS

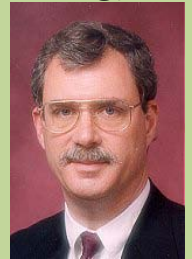
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