

LUPUS

Symptoms or Behaviors

- Joint Ache
- Frequent fevers of more than 100°
- Arthritis (swollen joints)
- Headaches
- Prolonged or extreme fatigue
- Skin rashes
- Anemia
- Kidney involvement
- Pain in the chest on deep breathing (pleurisy)
- Butterfly-shaped rash across the cheek and nose
- Hair loss
- Sensitivity to sun
- Purple fingers and toes from cold and stress
- Seizures
- Depression

About the Disorder

Lupus is a widespread and chronic (lifelong) autoimmune disease. It is a disease that can affect almost every organ in the body. It causes symptoms that can vary from very mild to life threatening. Lupus can affect many parts of the body, including the joints, skin, kidneys, heart, lungs, blood vessels and brain.

The immune system normally protects the body against viruses, bacteria, and other foreign materials. In an autoimmune disease like lupus, the immune system loses its ability to tell the difference between foreign substances and its own cells and tissue. The immune system then makes antibodies directed against "self". This self destruction causes inflammation and damages various body tissues.

Lupus is NOT contagious. Researchers do not know what causes lupus. While scientists believe there is a genetic predisposition to the disease, it is known that environmental factors also play a role in triggering the disease. Some of the factors that may trigger lupus include infections, antibiotics, ultraviolet light, extreme stress, certain drugs, and hormones.

The Lupus Foundation of America estimates that approximately 1,500,000 Americans have a form of the disease. It occurs 10 to 15 times more frequently in adult females than adult males. This may be due to hormonal factors. Lupus develops most often between ages 15 and 44. It is two to three times more common in African Americans, Hispanics, Asians, and Native Americans than in Caucasians. Only 10 percent of people with lupus will have a close relative (parent or sibling) who already has lupus or may develop lupus and only about 5 percent of the children born to individuals with lupus will develop the illness.

How is lupus diagnosed?

Because many lupus symptoms mimic other illnesses, are sometimes vague, and may come and go, lupus can be difficult to diagnose. Diagnosis is usually made by a careful review of a person's entire medical history, a physical examination, coupled with an analysis of the results obtained in routine laboratory tests and some specialized tests related to immune status. Currently, there is no single laboratory test that can determine whether a person has lupus or not. It may take months or even years for doctors to piece together evolving symptoms and accurately diagnose lupus.

How is lupus treated?

There is no cure for Lupus. Treatment approaches are based on the specific needs and symptoms of each person. Medications are often prescribed for people with lupus, depending on which organs are involved, and the severity of involvement. The commonly prescribed medications include: nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, corticosteroids, antimalarials, and immunomodulating drugs.



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Educational Implications

Fatigue and medication side effects

Children with lupus may experience extreme levels of fatigue, making participation in school difficult. Treatment may include dosages of corticosteroids and NSAIDs that produce side effects such as weight gain, a rounded, puffy face, stomach upset, diarrhea, emotional ups and downs, acne, unwanted hair growth, and stretch marks. These changes may be visible to other children and may be upsetting to the child.

Cognitive Dysfunction

At some point during the course of their lupus, up to 50 percent of lupus patients describe feelings of confusion, fatigue, memory impairment, and difficulty expressing their thoughts. This collection of symptoms is called cognitive dysfunction and is found in people with mild to moderately active Systemic Lupus Erythematosus (SLE). This difficulty along with the psychological problems of having a serious chronic disease can impact a child's ability to attend, focus and complete assignments in school.

Lupus Headache

Approximately 20 percent of patients with SLE experience severe headaches which are related to the disease and known as lupus headache.

Instructional Strategies and Classroom Accommodations

- Support and counseling for emotional liability. Frequently there are periods of anger and depression. Some children require psychological intervention. Improperly dealt with, a child's resentment about having lupus may result in risky behavior that could affect their well-being.
- Educate the school faculty to explain:
 - absences for doctor's visits
 - fatigue
 - changed appearance
 - restrictions in activities.
- Schedule adequate rest and quiet times.
- Limit exposure to sunlight which can worsen symptoms.
- Make sure there is emergency information which can be easily accessed. A "medic alert" bracelet should be considered for any child or teenager who is on chronic corticosteroid therapy.
- Provide accommodations and modifications as necessary due to cognitive dysfunction, frequent absences and/or fatigue.
- School nurse may need to develop an Individual Healthcare Plan.

Resources

Lupus Foundation of America, Inc.

www.lupus.org

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Washington, DC 20036

Phone 202-349-1155

Fax 202-349-1156

A tremendous amount of information about the disease, new research and connections to local chapters and support groups.

Loopy Lupus Helps Tell Scott's Story About a Disease Called Lupus

A young boy's story of lupus and how he lives with it, as told by his illustrated friend *Loopy Lupus*.

Dedicated to all the children and their families affected by lupus.

Lupus Foundation of America, Inc.

2002. Booklet, 34 pp. \$8.95

Lupus Now - the official magazine of the Lupus Foundation of America. The magazine is published three times each year (winter, spring, fall) and includes 48 pages of the latest information on a variety of lupus-related topics. It is the source that people with lupus, their families, and their physicians turn to for timely, accurate and interesting information. It includes lifestyle and wellness feature articles, the latest in treatments and therapies, clinical updates, and personal stories and more.

You may purchase an individual subscription for \$25/year by calling the LFA Toll Free Number 1-888-38-LUPUS or 1-(202)-349-1155 M-F, 9 AM - 5 PM ET

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