



PATIENT FACT SHEET

Systemic Lupus Erythematosus (Juvenile)



CONDITION DESCRIPTION

Systemic lupus erythematosus (SLE) is a disease where the immune system is overactive and doesn't function properly. It attacks the body's organs by mistake, causing inflammation in skin, joints, kidneys, lungs or the nervous system. SLE may flare at times or go into remission, where the disease is inactive.

About 20% of people with SLE develop it before age 20. It's rare before age 5, and more common in females,

and among African-Americans, Hispanics, South or Southeast Asians, and North American First Nations populations.

SLE's cause is unknown. Environmental factors, genes or hormones may play a role. It is not contagious. Each child with SLE has a different disease course, and will have a unique treatment plan.



SIGNS/ SYMPTOMS

Children with lupus often have symptoms like these: fever, fatigue, weight loss, arthritis or joint pain. "Butterfly" rash across the cheeks and the bridge of the nose or other rashes may occur. Other symptoms include mouth or nose sores, seizures or other nervous system problems, fluid around the heart or lungs, kidney problems, and blood problems like anemia, bruising, low platelets or low white blood cell counts.

To diagnose juvenile lupus, a child must have at least four physical symptoms and an abnormal blood test for the presence of certain auto-antibodies. In lupus, auto-antibodies attack healthy tissue and organs. Lupus may be life-threatening if organs like the heart, kidneys, lungs or brain are affected.

Children with lupus nearly always test positive for antinuclear antibodies (ANA), but this test is not specific for lupus diagnosis. Healthy children and those with other illnesses may also test positive for ANA.



COMMON TREATMENTS

Treatment for juvenile lupus aims to stop inflammation and prevent organ damage. A pediatric rheumatologist should carefully monitor the child's treatment. Corticosteroids, such as prednisone, stop inflammation and may be used for several years.

Common treatments include hydroxychloroquine (Plaquenil), as well as other immune-suppressing drugs like azathioprine (Imuran), mycophenolate mofetil (CellCept), methotrexate (Rheumatrex, Trexall, Otrexup, Rasuvo), cyclophosphamide (Cytoxan) and

rituximab (Rituxan). Nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen (Advil, Motrin) or naproxen (Aleve, Naprosyn) may be taken for pain.

All medications for lupus may have side effects. Corticosteroids may cause high blood pressure, weight gain, depression, osteoporosis, stretch marks, cataracts and glaucoma. A pediatric rheumatologist will evaluate the response to treatment and make adjustments if needed.



CARE/ MANAGEMENT TIPS

Children and teens may help prevent lupus flares by protecting their skin from sunlight. They should wear long sleeves, hats and sunscreen when going outdoors. They should get adequate rest and take their recommended medications. To reduce osteoporosis risk from steroids, they may need extra calcium or vitamin D. Children and teens with lupus should try to live as normal a lifestyle as possible, including school, activities

with friends, a healthy diet and exercise. It's important to follow up with doctor's appointments, stay informed about their disease, talk with their health care team and get necessary blood tests.

If a child or teen becomes sad or depressed about their lupus, talking with a social worker, counselor, pediatric rheumatology nurse, or juvenile lupus support group may be helpful.

Updated March 2017 by Ziv Paz, MD and reviewed by the American College of Rheumatology Committee on Communications and Marketing. This patient fact sheet is provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnosis and treatment of a medical or health condition.