

# LUPUS FACT SHEET

## Overview

- Systemic lupus erythematosus (SLE or lupus) is a chronic autoimmune disorder that can affect virtually any organ of the body. In lupus, the body's immune system, which normally functions to protect against foreign invaders, becomes hyperactive, forming antibodies that attack normal tissues and organs, including the skin, joints, kidneys, brain, heart, lungs and blood. Lupus is characterized by periods of illness, called flares, and periods of wellness, or remission.
- Lupus is difficult to diagnose because its symptoms come and go, mimic those of other diseases, and there is no single laboratory test that can definitively prove that a person has the complex illness.
- To date, lupus has no known cause or cure. Early detection and treatment is the key to a better health outcome and can usually lessen the progression and severity of the disease.
- Lupus is one of America's least recognized major diseases. While lupus is widespread, awareness and accurate knowledge about it is lacking.

## Prevalence and Disease Burden

- Research indicates that about 1.5 million Americans have lupus<sup>1</sup>. In fact, more Americans have lupus than AIDS, cerebral palsy, multiple sclerosis, sickle-cell anemia, or cystic fibrosis, making it one of this country's most prevalent medical problems.
- Ninety percent of those diagnosed with lupus are women, and the onset of the disease usually occurs during childbearing age, between the ages of 15 and 44. African American women are three times more likely to get lupus than white women. It is also more common among Hispanic/Latina, Asian and American Indian women. However, lupus also strikes children, men and older adults.
- Death rates from lupus are on the rise. A recent report from The Centers for Disease Control and Prevention revealed a 60-70 percent upsurge in lupus deaths between 1979 and 1989. Lupus is responsible for high percentage of the mortalities caused by rheumatic conditions.<sup>2</sup>
- Lupus is a leading cause of kidney disease, stroke and premature cardiovascular disease in young women.

## Types of Lupus

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<sup>1</sup> Bruskin/Goldring Research, 1994

<sup>2</sup> Sacks JJ, Helmick CG, Langmaid G, Sniezek JE. Trends in deaths from systemic lupus erythematosus in United States, 1979-1988. *MMWR* 2002;51(17):371-374.

Although "lupus" is used as a broad term, there actually are several different types of lupus:

- Systemic lupus erythematosus (SLE) is the form of the disease that most people refer to when they say "lupus." The word "systemic" means the disease can affect many parts of the body — including the kidneys, brain or central nervous system, blood and blood vessels, skin, lungs, heart and joints.
- Discoid lupus erythematosus mainly affects the skin. A rash, which appears on the face, scalp, or elsewhere, may last for days or years, and can recur.
- Drug-induced lupus is triggered by a few medications, but usually goes away when the medicine is stopped. The symptoms in this form of lupus usually are milder.

### Diagnosis of Lupus

- Lupus is extremely difficult to diagnose. No single test can definitively determine whether a person has lupus -- but several laboratory tests of blood and urine can help the doctor with the diagnosis. The most common blood tests used in the diagnosis of lupus are:
  - Anti-nuclear antibody test (ANA) to determine if autoantibodies to cell nuclei are present in the blood.
  - Anti-DNA antibody test to determine if there are antibodies to the genetic material in the cell.
  - Anti-Sm antibody test to determine if there are antibodies to Sm, a protein found in the cell nucleus.
- A new diagnostic screening test was recently approved by the FDA -- the anti-SR protein antibody assay -- that can identify 50-70 percent of lupus patients who react positively to the SR proteins.
- Other diagnostic tools include a medical history, complete physical exam and a skin or kidney biopsy, which can show signs of an autoimmune disease. During the physical, the doctor will look for rashes and other signs that something is wrong.
- Signs and symptoms that suggest lupus include:
  - Painful or swollen joints
  - Fingertips and/or toes become pale or purple from the cold or stress
  - Sores in the mouth or nose
  - Low blood count
  - Red rash or color change on the face, across the cheek or bridge of nose
  - Unexplained fever for several days
  - Chest pain associated with breathing
  - Protein in the urine
  - Extreme fatigue -- feeling tired all the time
  - Sensitivity to the sun
  - Depression, trouble thinking, and/or memory problems
  - Unusual hair loss, mainly on the scalp

## Treatment for Lupus

- Since lupus is highly individualized, and no two cases are exactly alike, the treatment also varies depending on the symptoms and needs of the patient.
- Lupus is usually treated by a rheumatologist who specializes in treating diseases that affect the joints and muscles.
- Creams are often prescribed for a rash. For more serious problems, anti-inflammatory drugs, anti-malarials, and steroids, such as cortisone, are used to treat lupus. Cytotoxic chemotherapies similar to those given in the treatment of cancer are also used to suppress the immune system in lupus patients.
- No major new treatment for lupus has been developed in more than 40 years, and lupus treatments can cause as much damage to a patient's system as the disease itself.

## Economic Impact of Lupus

- Several studies suggest that the average annual cost to provide medical treatment for a person with lupus is nearly \$60,000<sup>3</sup>. However, for some lupus patients, medical costs may exceed several thousand dollars every month. Many people with lupus receive their health care through a government-sponsored program such as Medicare or Medicaid.
- According to a public biotechnology company developing therapeutics for antibody-mediated autoimmune diseases, SLE accounts for more than 77,000 hospital admissions in the U.S. each year, averaging 10 days.
- Kidney dialysis, required by some people with lupus, costs more than \$68,000 per patient per year in the U.S.<sup>4</sup>. Hip replacement surgery, which may be required as a result of the side effects of high-dose corticosteroid therapy, costs about \$62,000<sup>5</sup>.

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<sup>3</sup> G. Gironimi et al. 1996 *Arthritis & Rheumatism* 39:979-87. Costs translated to 2008 dollars.

<sup>4</sup> Economic Costs of ESRD, *Per person per year costs:dialysis patients (2005)*

<sup>5</sup> <http://archives.cnn.com/2000/HEALTH/12/05/hip.replacement/index.html> (adjusted for 2008 dollars)