

PATIENT RESOURCE GUIDE

What you should  
know about  
**Lupus**



Lupus is a chronic, complex and prevalent autoimmune disease that affects more than 1.5 million Americans. It is a disease that is often overlooked, misdiagnosed and misunderstood. It's important to know as much as you can about lupus symptoms, diagnosis and treatment so you can take an active role in your care.

## What is lupus?

Lupus is a disease that “attacks” your own body. The immune system is the body’s natural defense against disease. In lupus, the immune system, which is designed to protect against infection, creates antibodies that attack the body’s own tissues and organs.

Some people with lupus experience serious, life-threatening problems. But for most, lupus can be controlled with medicines and lifestyle changes.

## What are the different types of lupus?

The two most common types of lupus are systemic lupus erythematosus (SLE) and cutaneous lupus. SLE is the form of the disease that most people mean 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 of the circulatory system, skin, lungs, heart, and joints.

Cutaneous lupus affects your skin. There are many different types of lupus skin rashes. One of the common types of skin lupus is called discoid lupus erythematosus (DLE) and is identified by a rash that may appear on the face, neck or scalp, and by hair loss. Exposure to sunlight or fluorescent light can cause a rash to appear or worsen.

About 1 in 10 people with discoid lupus eventually develop systemic lupus, and about 3 in 10 people with systemic lupus also have discoid lupus rashes.

Far less common, drug-induced lupus can develop with certain medicines. In rare cases, certain prescription medicines can cause SLE symptoms. Symptoms can appear even months after starting the medicine but usually disappear some time after the medicines are stopped.

## What causes lupus?

The cause of lupus remains unknown. You can't “catch” lupus or “give” it to someone else. Ten percent of lupus patients have a first-degree relative (parents, siblings, children) or a second-degree relative (aunt, uncle, first cousin) with lupus. It is believed that people with lupus have a genetic pre-disposition, and something in the environment triggers the onset of the disease. External factors that are possible triggers include ultraviolet rays, virus, exhaustion, infection, trauma, and stress. Researchers are also looking at the possible role of female and male hormones.

## Who is most likely to get lupus?

Females are at greater risk, but lupus also occurs in males. Lupus can develop at any age but usually occurs among people between the ages of 15 and 45.

## Lupus in the U.S.

Approximately 1.5 million Americans have lupus.

- ▶ 9 in 10 people with lupus are female.
- ▶ Lupus is 2 to 3 times more prevalent in African Americans, Hispanics/Latinas, Asians, and Native Americans than Caucasians.
- ▶ 1 in 5 people with lupus are children, under age 20.
- ▶ Lupus is a leading cause of kidney disease, stroke, and heart disease in women of childbearing age.



## What are the most common symptoms?

Lupus symptoms vary widely. If you have any of the following common signs and symptoms, ask your healthcare provider about lupus:

### Lupus Signs and Symptoms

- ▶ Achy joints (arthralgias)
- ▶ Fever over 100 degrees F
- ▶ Swollen and painful joints (arthritis)
- ▶ Prolonged fatigue
- ▶ Skin rashes
- ▶ Anemia
- ▶ Swollen ankles (kidney involvement)
- ▶ Chest pain upon deep breathing (pleurisy)
- ▶ Butterfly-shaped rash across cheeks and nose
- ▶ Sensitivity to sun (photosensitivity)
- ▶ Unusual hair loss
- ▶ Problems with abnormal blood clotting
- ▶ Pale or purple fingers from cold or stress
- ▶ Seizures
- ▶ Mouth ulcers (often painless, at roof of mouth)



If you have been diagnosed with lupus, these symptoms may indicate increased activity of the disease, known as a flare. People with lupus can also go into periods of remission when few or no symptoms are present.

### How is lupus diagnosed?

No single lab test can determine if you have lupus. Many symptoms of lupus are very similar to those of other diseases, and can come and go. Your primary care doctor or rheumatologist will use your medical history, a physical exam, and several laboratory tests to determine if you have lupus.

Four or more of the following “Eleven Criteria of Lupus” established by the American College of Rheumatology are usually present before a diagnosis of lupus is made.

### The “Eleven Criteria of Lupus”

- 1 **Malar rash** – butterfly-shaped rash across cheeks and nose
- 2 **Discoid (skin) rash** – raised red patches
- 3 **Photosensitivity** – unusually strong reaction to sunlight. Sun exposure may cause a skin rash or trigger a flare.
- 4 **Mouth or nose ulcers** – usually painless
- 5 **Nonerosive arthritis** – (bones around joints do not get destroyed) in 2 or more joints with tenderness, swelling or effusion
- 6 **Cardio-pulmonary involvement** - inflammation of the lining around the heart (pericarditis) and/or lungs (pleuritis)
- 7 **Neurologic disorder** - seizures and/or psychosis
- 8 **Renal (kidney) disorder** - excessive protein in the urine, or cellular casts in the urine
- 9 **Hematologic (blood) disorder** - hemolytic anemia, low white blood cell count, or low platelet count
- 10 **Immunologic disorder** - antibodies to double stranded DNA, antibodies to Sm, or antibodies to cardiolipin
- 11 **Antinuclear antibodies (ANA)** – positive test in absence of drugs known to induce it

### Does a positive Antinuclear Antibody (ANA) test mean I have lupus?

Not necessarily. A “positive” ANA blood test indicates that the immune system is making an antibody (a protein) that reacts with the body’s own cells — a condition called autoimmunity that may or may not be harmful.

The ANA test is just one of the 11 criteria a healthcare provider uses to help make a diagnosis.

## What is the treatment for lupus?

While there is no cure, there are treatments. Early diagnosis and appropriate treatment can help keep the symptoms of the disease under control and lessen the chance of permanent damage to organs or tissues. Once a diagnosis is made, it's very important that major organs (the central nervous system, kidneys, heart, lungs) are regularly monitored for problems. Treatment depends on the activity and extent of the disease — no two cases of lupus are alike.

### Medicines used for lupus include:

- ▶ **NSAIDs** – nonsteroidal anti-inflammatory drugs to relieve achy joints and arthritis in mild SLE when pain is limited and organs are not affected.
- ▶ **Antimalarial drugs** – such as hydroxychloroquine, often prescribed for arthritis or skin problems.
- ▶ **Corticosteroids** – usually prednisone, used for major organ involvement. The dosage prescribed depends on which organs are involved, the severity of symptoms, and blood test results.
- ▶ **Other immunosuppressive agents** – such as azathioprine, methotrexate, cyclophosphamide, cyclosporine, and mycophenolate mofetil. These very potent drugs help control the overactive immune system in lupus patients. They help limit damage to major organs and are closely monitored to counter the potentially serious side effects and complications.
- ▶ **Biologics** – belimumab (Benlysta®), the first medication specifically developed for lupus in over 50 years, approved in 2011. Belimumab is an antibody that seems to reduce the body's ability to attack its own tissues.

While medicines used to treat lupus save lives, many cause unpleasant side effects. Lupus Research Institute investigators and others worldwide are working very hard to develop safer and more effective treatments.

## Lifestyle changes that may help with lupus:

- ▶ **During a “flare”** – get plenty of rest.
- ▶ **When in remission** – exercise to increase joint flexibility and muscle strength.
- ▶ **Avoid sunlight** – since the sun can trigger a flare, always apply sunscreen that blocks UVB and UVA rays (365 days a year) and regularly wear hats and other protective clothing.
- ▶ **Make de-stressing a priority** – support groups, professional counseling, and talking with friends, family and physicians can help a lot. Learn relaxation techniques like deep breathing. Find what works for you.
- ▶ **Get regular checkups** – these usually include blood and urine tests.
- ▶ **Ask questions** – when in doubt, call your doctor as soon as possible. If you are having new side effects or symptoms, a change in treatment might be needed.

## What is the outlook for people with lupus?

Researchers are making tremendous progress in developing ways to better identify, diagnose, and treat lupus and its potential complications. More promising medicines for lupus are in development than ever before.

However, for the promise of safer, more effective medications to be fulfilled, everyone's participation is needed for them to be tested and approved. There are many types of clinical studies – not all require taking an experimental drug. Learn more at [LupusTrials.org](http://LupusTrials.org).

With your involvement as a person with lupus or as someone who cares, transforming lives today is within reach as we move toward preventing and curing lupus tomorrow.

# ABOUT

## THE LUPUS RESEARCH INSTITUTE

The Lupus Research Institute (LRI), the world's leading private supporter of novel research in lupus, pioneers discovery and champions scientific creativity as it has successfully demonstrated the power of innovation to propel scientific solutions in this complex autoimmune disease.



**Lupus  
Research  
Institute**

330 Seventh Avenue Suite 1701  
New York, NY 10001  
Phone: 212-685-4118  
[LupusResearchInstitute.org](http://LupusResearchInstitute.org)