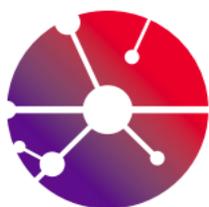


# What You Need to Know About **Lupus**



**LUPUS  
RESEARCH  
ALLIANCE**

*Breaking through.*



Lupus is a chronic and complex autoimmune disease that affects millions worldwide. It is a disease that is often overlooked, misdiagnosed and misunderstood. So it's important to know as much as you can about lupus symptoms, diagnosis and treatment. Taking an active role in your health helps you get the best possible care and improves the outlook for your future.

## What is lupus?

Lupus is a disease where the immune system attacks instead of protects. The immune system is the body's natural defense against disease. In lupus the immune system creates antibodies that attack the body's own tissues and organs.

Everyone reacts to lupus differently. Some people with lupus experience serious, life-threatening problems. But for most, lupus can be kept under control 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 the skin.** There are many different types of lupus skin rashes. One of the common types of skin lupus is called discoid lupus erythematosus (DLE). It 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.



Much less common, drug-induced lupus can develop with certain medicines. Symptoms are usually milder, and most go away after the medicines are stopped.

Neonatal lupus is a rare type of lupus that affects newborns.



## Does lupus run in families?

Genetics may be a risk factor for lupus. Ten percent of lupus patients have a first-degree relative (parents, siblings, children) or a second-degree relative (aunt, uncle, first cousin) with lupus. Many have relatives with other autoimmune diseases.

## What causes lupus?

The cause of lupus remains unknown. You can't "catch" lupus or "give" it to someone else. It is believed that people with lupus may be predisposed to the disease because of their genes. Also, the environment may trigger the disease to start. External factors that are possible triggers include sunlight, viruses, fatigue, infection, trauma and stress. Researchers are also looking at the possible role of female and male hormones.

## Lupus in the U.S.



● **9 in 10** people with lupus are female. But men can also have lupus.

● Lupus is **2 to 3** times more common in African Americans, Hispanics/Latinas, Asians, and Native Americans than Caucasians.

● **1 in 5** people with lupus are under age 20.

## Who is most likely to get lupus?

Females are at the most risk but lupus can also affect males. Lupus can develop at any age, including childhood, but most often starts between the ages of 15 and 45.

## Common symptoms include:

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

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



You may also have these symptoms when the disease becomes more active – a phase called a flare. People with lupus can also go into remission, when they have few or no symptoms.

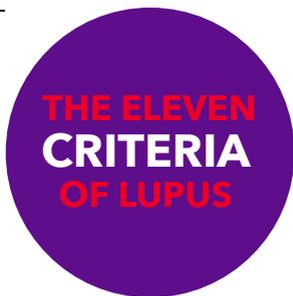
## How is lupus diagnosed?

No single lab test can tell if you have lupus.

Many symptoms of lupus are like those of other diseases and can come and go. Your primary care provider or rheumatologist will use your medical history, a physical exam and several laboratory tests to determine if you have lupus.

At least **4** of the **Eleven Criteria of Lupus** from the American College of Rheumatology are usually present for lupus to be diagnosed.

- 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 can cause a skin rash or trigger a flare.
- 4 Mouth or nose ulcers** – usually painless
- 5 Nonerosive Arthritis** – inflammation in 2 or more joints with tenderness, swelling or effusion (discharge). Nonerosive means that bones around joints do not get destroyed.
- 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** – increased protein in the urine, or clumps of red blood or kidney cells in the urine called cellular casts
- 9 Hematologic (blood) disorder** – anemia caused by damage to red blood cells, low white blood cell count, or low platelet count



- 10 Immunologic disorder** – antibodies to double stranded DNA, antibodies to Sm (a chemical element in the body), or antibodies to cardiolipin (a kind of fat in the blood)
- 11 Antinuclear antibodies (ANA)** – positive blood test in absence of drugs known to induce it

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

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

The ANA test is just one of the 11 criteria a healthcare provider uses to diagnose lupus.

## What is the treatment for lupus?

While there is no cure, there are treatments. Early diagnosis and appropriate treatment can help control symptoms and lessen possible damage to organs or tissues.

Once a diagnosis is made, it’s very important to see a healthcare provider often. He/she can look for changes in symptoms, predict and prevent flares, spot side effects of medications and change the treatment plan if needed. Regular visits help monitor major organs (the central nervous system, kidneys, heart, lungs) early for any problems. Treatment differs for each person — no two cases of lupus are the same. A list of medicines follows on the next page.



## Medicines used for lupus depend on the symptoms and include:

- **NSAIDs** – nonsteroidal anti-inflammatory drugs are used to relieve mild pain, achy joints and arthritis in mild SLE.
- **Antimalarial drugs** – such as hydroxy-chloroquine, are often prescribed to lessen inflammation in joints and other organs and to treat skin rashes.
- **Corticosteroids** – (usually prednisone) are used to decrease the swelling and pain of inflammation by lessening the immune response.
- **Other immunosuppressive agents** – such as azathioprine, methotrexate, cyclophosphamide, cyclosporine and mycophenolate mofetil. These very potent drugs help suppress or control the overactive immune system in lupus and help limit damage to major organs. Their use is closely monitored to manage possible side effects and complications.
- **Biologics** – The only new drug developed specifically for lupus since 1955, belimumab (Benlysta®) is a biologic that seems to lessen the body's ability to attack its own tissues.



While lupus treatments save lives, many cause unpleasant side effects. Researchers worldwide are working hard to understand the disease so it can be better managed. Many Lupus Research Alliance-funded researchers are learning how and why lupus affects different organs and are developing biomarkers to detect and monitor

disease progression. Others are using their grants to uncover the underlying causes so one day a cure can be found.

The Lupus Research Alliance also launched the Lupus Clinical Investigators Network (LuCIN) to speed up development of new lupus treatments. Made up of lupus experts throughout North America, LuCIN provides a framework to test new drugs as well as existing medications as possible treatments for lupus. Researchers also aim to involve patients as active members in the research process. Visit [lupusresearch.org/lucin](http://lupusresearch.org/lucin) to learn how you can help advance new treatments for lupus.

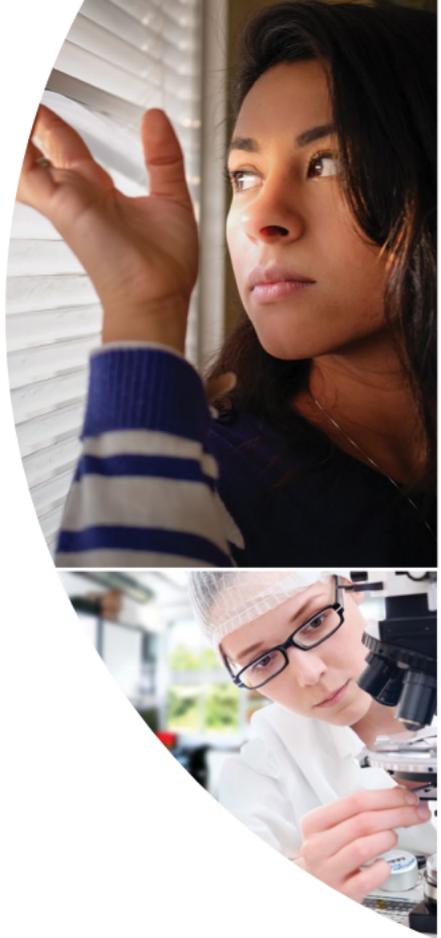
## Who treats lupus?

Lupus is often managed by a team of healthcare providers who are experts in particular areas of the body. Most commonly your team is led by a rheumatologist who primarily treats diseases affecting the joints.



Specialist	Area of the Body Affected by Lupus
Cardiologist	heart/arteries/blood vessels
Dermatologist	skin
Endocrinologist	glands/hormones
Hematologist	blood
Immunologist	immune system
Nephrologist	kidneys
Neurologist	brain/nervous system
Psychiatrist, Psychologist Social worker	mental health





## ABOUT THE **LUPUS RESEARCH ALLIANCE**

The Lupus Research Alliance unites the global lupus community in bold determination to free the world of lupus through the power of science.

We will transform the lives of people affected by lupus as we welcome and embrace a new scientific era, pioneer innovation, push the frontiers of knowledge, enlist diverse new scientific talent, and lead the drive to new treatments, prevention and cure. Because the Board of Directors funds all Lupus Research Alliance administrative and fundraising costs, 100% of all other donations go directly to support research programs.

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