

Native Americans and Lupus

QUICK GUIDE



1 Facts about lupus

- People of all races and ethnic groups can develop **lupus**.
- Women develop lupus much more often than men: nine of every 10 people with lupus are women. Children can develop lupus, too.
- Lupus is much more common in Native Americans than other ethnic groups, and may occur in some tribes nearly ten times as often as among Caucasians.
- It is not known why lupus is more common in Native Americans. Some scientists think that it is related to genes, but we know that hormones and environmental factors play a role in who develops lupus. There is a lot of research being done in this area, so contact the LFA for the most up-to-date research information, or to volunteer for some of these important research studies.
- Some studies show that Native Americans develop lupus at a younger age than people from other ethnic groups and that the disease may be worse for Native Americans as well. The reasons for this are also unclear at this time.

2 What is lupus?

- Lupus is a **chronic autoimmune disease** that can damage any part of the body (skin, joints and/or organs inside the body). Chronic means that it is not curable, but with good medical care, most people with lupus can lead a full life.
- With lupus, something goes wrong with your **immune system**, which is the part of the body that fights off viruses, bacteria, and germs (“foreign invaders,” like the flu). Autoimmune means your immune system cannot tell the difference between these foreign invaders and your body’s healthy tissues and goes after healthy tissue as well. This causes **inflammation** (redness and swelling) and pain.
- People with lupus have **flares** (the disease gets worse and you feel bad) and **remissions** (the disease gets better and you feel good).
- Lupus can be mild or serious but should **always** be treated by a doctor.

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3 There are several types of lupus

- **Cutaneous (Discoid) lupus** affects only the skin and shows up as a rash, usually on the face, neck, and scalp. **Systemic lupus (SLE)** is more serious than cutaneous lupus and affects not only the skin but other parts of the body such as the joints, heart, lungs, kidneys, liver, brain, or blood. **Drug-induced lupus** is caused by taking certain types of medicines. It is usually not as serious and should go away when the person stops taking the medicine. Although it is rare, **neonatal lupus** can occur in the fetus of a woman with lupus. Symptoms range from a rash that goes away to a permanent heart defect.
- When people just say “lupus,” they generally are talking about systemic lupus.
- Lupus has also been called by other names such as “butterfly fever.”

4 What are the symptoms of lupus?

- Because lupus can affect any part of the body, the disease is different for everyone and no two people feel the same way.

The most common symptoms are:

- rash or redness on the face across the nose and cheeks (known as the “butterfly” rash)
- scaly rash that scars the skin
- sores in the nose or mouth
- joint pain and swelling
- fatigue (feeling very tired)
- fever and/or feeling of having the flu
- chest pain when breathing deeply
- unusual hair loss, usually on the scalp
- pale or purple fingers or toes from cold or stress
- getting a rash or feeling sick after being in the sun
- depression
- memory problems
- kidney disease (there are no obvious symptoms when people with lupus have kidney disease; it has to be shown by certain urine and blood tests)
- problems with the blood, such as anemia or low red blood cell count, which only show up in lab tests
- certain other blood test results

5 What causes lupus?

- No one knows what causes lupus. Scientists think that people are born with the genes to develop lupus and that something brings on or “triggers” the disease and symptoms.
- Some common lupus triggers are:
 - infection • certain medicines • sunlight • stress
- Lupus is not contagious. You *cannot* “catch” lupus and you cannot “give” it to anyone.



Because the disease is different for each person, not everyone will take the same medicines.

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What is the treatment for lupus?

- There is no cure for lupus, but there are medicines to help a person feel better.
- Because the disease is different for each person, not everyone will take the same medicines.
- Many people with systemic lupus are treated by a **rheumatologist**. People with cutaneous (discoid) lupus are treated by a **dermatologist**.
- It is very important to keep taking all of the medicines your doctor prescribes, not to stop taking any medicines without talking with your doctor first, and to tell your doctor about any new symptoms.
- Also, tell your doctor if you are taking any herbs or supplements, or if you are planning to add them to your diet. There may be interactions with medications, and we don't yet know whether traditional therapies will be helpful or harmful for people with lupus.
- Sometimes it may seem like folk remedies, such as magnets or copper bracelets, are stopping pain or easing stiffness, but the truth is that the symptoms of lupus can come and go. So far the scientific studies of magnets and copper have not found proof that they are effective in relieving pain or any other symptoms. That doesn't mean you should stop using them if you find them helpful, but you shouldn't rely on them instead of medication your doctor prescribes.

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How do you know if you have lupus?

- There is no single test to see if you have lupus. One blood test that doctors use is the ANA test, which measures activity by your immune system against certain foreign invaders. About 97 percent of people with lupus test positive for ANA. However, people with other diseases also test positive for ANA, and even people with no illness can test positive. On the other hand, it is very rare for a person who has lupus to test negative for ANA.
- Since so many other diseases can look like lupus, doctors use 11 criteria (symptoms and laboratory test results) to help tell if you have lupus. You must have had at least four of the 11 to have lupus.
- Because you do not have to have all of the symptoms at the same time, it is very important to tell your doctor about any health problems you have had over the years. It is also important to let your doctor know if anyone in your family—parents, brothers, sisters, grandparents, aunts, or uncles—has lupus or another autoimmune disease.



Low-impact exercise can help keep you strong and give you energy.

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Living with lupus: If you have lupus, you should...

- **Protect yourself from the sun.** People of all skin colors with lupus are often very sensitive to sunlight, and exposure to the sun may trigger a flare. So try to stay out of the sun, especially between 10:00 a.m. and 4:00 p.m. Use sunscreen and wear a hat and other sun-protective clothing when you go outdoors, even if it's cloudy.
- **Eat a well-balanced diet.** There is no special diet for lupus, but you should try to maintain a healthy diet, one that contains plenty of fruits, vegetables, and foods that are low in fat, salt, and sugar.
- **Exercise regularly and moderately.** Low-impact exercise can help keep you strong and give you energy.
- **Don't smoke.** Chemicals in cigarette smoke make symptoms of lupus worse. Avoiding areas with heavy cigarette smoke is also recommended, because of additional dangers of second-hand smoke.
- **Get plenty of rest.** Alternate rest periods with activities. Staying in bed can cause muscles to become weak, but too much activity can cause lupus to flare.
- **Talk to your doctors if you are planning to get pregnant.** Lupus pregnancies are high-risk and need to be planned and managed by you and your medical team.
- **Call your doctor if your temperature is over 99.6.** This could mean an infection or a lupus flare.
- **Understand that depression can be caused by lupus.** Feeling overwhelmed, hopeless, or helpless are all symptoms of depression. Depression is very common for people with lupus, but it can be treated and controlled.
- **Reach out to the people in your support system.** They may be family, friends, neighbors, members of a group you belong to, or co-workers. Remember that knowing others care about you can have a positive influence on your health.



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The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable, and devastating diseases, while giving caring support to those who suffer from its brutal impact. Through a comprehensive program of research, education, and advocacy, we lead the fight to improve the quality of life for all people affected by lupus. Contact the LFA or a chapter that serves your area to find out how you can become involved in our mission and how we can help you.

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