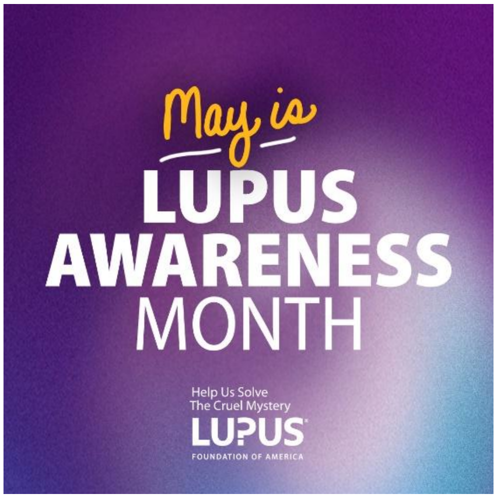
Let’s Make Lupus Visible!



Lupus is sometimes considered an “invisible illness” because its symptoms can be hard for others to recognize. CDC and partners are working to make lupus visible. We do this by raising awareness about lupus during Lupus Awareness Month in May and year-round. Read on to learn more about lupus and share this information in your community.

Lupus is a lifelong chronic autoimmune disease. Autoimmune diseases happen when the body's immune system attacks its own healthy cells and tissues, leading to inflammation and damage in organs or systems. The CDC National Lupus Registry estimates that over 200,000 Americans have the most common form of lupus, systemic lupus erythematosus. Anyone can develop lupus, but it is estimated that 9 out of every 10 people with lupus are women.

What is lupus?

Lupus is a chronic autoimmune disease that can cause inflammation and pain in any part of the body. Inflammation occurs when the body does not recognize and remove harmful agents. This can cause redness, pain, and swelling anywhere or all over the body, affecting the joints and muscles leading to possible loss of organ function. There are several different types of lupus that affect various organs and organ systems, such as the kidneys, heart, lungs, blood, joints, and skin.

Types of Lupus

- ***Systemic lupus erythematosus (SLE)*** is the most common form of lupus. It can affect a person's joints, skin, brain, lungs, kidneys, and blood vessels. This form of lupus is more likely to occur in people from racial and ethnic minority groups when compared to non-Hispanic White people.
- ***Cutaneous lupus*** is a skin disease that affects people with or without SLE in the form of a rash or lesions. There are two major forms – discoid lupus erythematosus (DLE) and subacute cutaneous lupus erythematosus.
- ***Neonatal lupus*** occurs when a developing baby is exposed to lupus in the womb during pregnancy. It can cause skin, liver, or blood problems, which can be treated at—or even before—birth.
- ***Drug-induced*** lupus is a short-term type of lupus caused by certain drugs.

Who is at risk for lupus?

Lupus can affect anyone. Women are most likely to be affected by lupus. Men and children can also be affected. Those with the highest risk for developing lupus are:

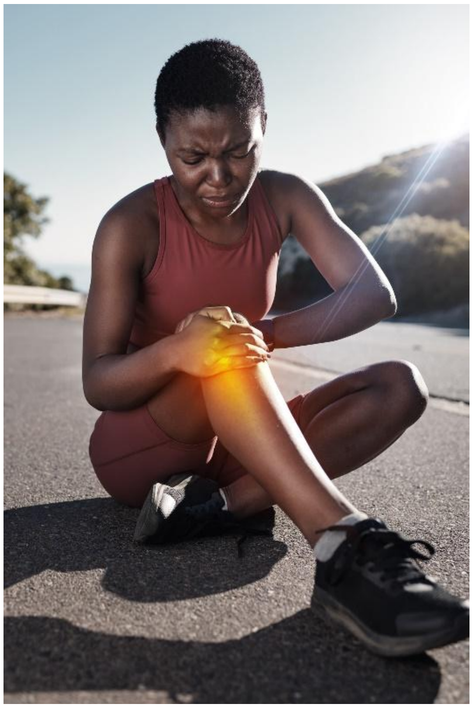
- Women, aged 15 – 44 years
- People from racial and ethnic minority groups
- People with a family history of lupus or other autoimmune diseases

Lupus occurs more often in women from racial and ethnic minority groups than in non-Hispanic White women. Black or African American and Hispanic women are often diagnosed with lupus at a younger age and have more severe symptoms and greater risk of developing other diseases and conditions than non-Hispanic White women. This can lead to lupus progressing further or faster and having greater risk of death. Social determinants of health (SDOH), along with hormonal and genetic factors, can lead to more severe disease and higher risk of death in racial and ethnic minority groups. Public health programs to reduce lupus among racial and ethnic minority groups should focus on the many factors that contribute to these disparities.

What are the symptoms of lupus?

Symptoms of lupus vary and can appear off and on for years. Because lupus can affect different parts of the body, it can cause a lot of different symptoms. Common symptoms include:

- Pain or swelling in the muscle and joints
- Extreme fatigue
- Butterfly rash on the cheeks and nose
- Swelling in hands, feet, or around the eyes
- Headache
- Fever
- Chest pain or breathing deeply
- Hair loss
- Fingers and toes feeling numb or turning white or blue (Raynaud's Disease)



How is lupus diagnosed?

Diagnosing lupus can be challenging because symptoms can vary from person to person, and they can come and go. There is no single test that can diagnose lupus. Sometimes it can take years to gather all the right information for an accurate diagnosis. Because diagnosis is difficult, it is important for women to recognize the symptoms and receive a diagnosis as early as possible. The sooner someone is diagnosed, the sooner they are on their way to managing their symptoms and avoiding the potential for long-term damage to their health. Women can track any symptoms and share them with their doctors. Typically, health care professionals must assess medical history, family history, symptoms, and laboratory tests to make a diagnosis.

How is lupus treated?

Lupus is a chronic disease with no cure. However, treatment is available to help manage its symptoms. Treatment can help improve symptoms, prevent flares, and prevent other health problems caused by lupus. Treatment depends on a patient's symptoms and needs. If women experience symptoms, they should start by seeing a primary care doctor and a rheumatologist, a doctor who specializes in the diseases of joints, muscles, and systematic autoimmune diseases such as lupus. Women with lupus may need to see other types of doctors as well. These may include nephrologists, who treat kidney problems, and clinical immunologists, who treat immune system disorders.

Kidney impairment or lupus nephritis is one of the most serious side effects of SLE. Those most affected by this form of lupus are women who are Black or African American, Hispanic/Latina, and Asian American. Black or African American women have a higher risk of progression to end-stage renal disease (ESRD) than other racial and ethnic minority groups. People with lupus nephritis have a higher risk of requiring dialysis or a kidney transplant for treatment of their disease.

Women with lupus can safely get pregnant and most will have normal pregnancies and healthy babies. However, all women with lupus who get pregnant are considered to have a "high risk pregnancy."

How is lupus managed?

There's a lot of women can do to manage lupus. Women with lupus can have a typical lifespan and a high quality of life. Women can take steps to control symptoms, prevent lupus flares, and cope with the challenges of lupus. The best way to keep lupus under control is by following treatment plans and maintaining good general health. Women with lupus should:

- Learn how to tell that a flare is coming.
- See their doctors regularly.
- Limit the time spent in the sun and in fluorescent and halogen light.
- Get enough sleep and rest.
- Build a support system made up of trusted people they can go to for help.

Self-management education workshops can help people with lupus learn how to manage daily life, medications, and interactions with doctors, as well as improve energy and pain management. Visit Managing Lupus for more information about self-management education programs and other tools and resources that can improve quality of life for people living with lupus. Use of online tools and applications (apps) can be an important part of managing lupus. Strategies to Embrace Living with Lupus Fearlessly (SELF) is a free online self-management app designed to help women with lupus manage symptoms, stress, and medications, as well as work with their healthcare teams.

Despite best efforts to follow treatment plans and maintain good health, women may have times when their lupus symptoms become worse. Women can talk to their doctors about ways to relieve symptoms when this happens.

What is CDC doing to address lupus?

CDC supports national organizations, public health agencies, universities, and communities to undertake lupus awareness activities, epidemiologic research, and public health programs.

- CDC funds lupus awareness, education, and management activities such as Be Fierce, Take Control, The Lupus Initiative, the National Resource Center on Lupus, and The Expert Series podcast.

- CDC supports epidemiologic research on lupus, carries out research into lupus interventions, and undertakes pilot programs to inform lupus public health practice. Learn more about CDC lupus publications.
- CDC funds several population-based patient registries to better estimate how many people have doctor diagnosed SLE in certain racial and ethnic groups and what are their health outcomes after diagnosis with lupus. People who are diagnosed with lupus or are caregivers for persons with lupus can enroll in any one of the lupus registries, including RAY: Research Accelerated by You.

Resources

Help Us Solve The Cruel Mystery | Lupus Foundation of America

Could it be Lupus? | Lupus Foundation of America

National Resource Center on Lupus | Lupus Foundation of America

National Lupus Patient Registry | Lupus Foundation of America

PULSE | Lupus Foundation of America

RAY: Research Accelerated by You | Lupus Foundation of America

Be Fierce, Take Control

SELF App