

→ Of the 1.5 million Americans with lupus, **90% are women** aged 15-44.

→ Lupus is one of the **top 20 leading causes of death** in women aged 5-64.

→ Research shows that **1 in 250** African American women will develop lupus.



Lupus is a chronic, life-altering disease that causes the body's autoimmune system to attack its own tissues and organs. Currently, there is no cure for lupus.

Typically, when people speak of lupus, they are referring to **Systemic Lupus Erythematosus (SLE)**. This is the most common type of lupus, accounting for 70% of all lupus cases. SLE—the focus of this fact sheet—can impact multiple organs, such as the heart, lungs, kidneys (lupus nephritis), or brain.

There are three other types of lupus:

Cutaneous lupus affects only the skin and accounts for approximately 10% of all lupus cases; however, cutaneous lupus can be a manifestation of SLE.

Drug-induced lupus is caused by high doses of certain medications and accounts for approximately 10% of lupus cases. Drug-induced lupus presents with symptoms similar to SLE that resolve when the medication(s) are discontinued.

Neonatal lupus is a result of antibodies that pass from mother to child during pregnancy and accounts for roughly 10% of lupus cases. The baby may be born with a skin rash, liver problems, or low blood counts. Typically, symptoms go away within six months and do not return.



Common Symptoms

- Fatigue
- Pain or swelling in the joints
- A butterfly-shaped rash on the cheeks and nose
- Swelling in the hands and feet, or around the eyes
- Headaches
- Hair loss
- Sores in the mouth or nose
- Low-grade fevers
- Sensitivity to sunlight or fluorescent light

Risk Factors

Several factors can increase the likelihood of developing lupus — including, sex, age, race and ethnicity, family history, and an existing diagnosis for another autoimmune disease. Below are specific factors that contribute to the risk of developing lupus:

Sex: Females are 9 times more likely than males to develop lupus

Age: Most people develop lupus between 15 and 44 years of age

Race/Ethnicity: Lupus is 2 to 3 times more prevalent in racial and ethnic minorities as compared to white people

Family history: Relatives of people with lupus have a 5 to 13% chance of developing lupus. However, only about 5% of children will develop lupus if their mother has it.

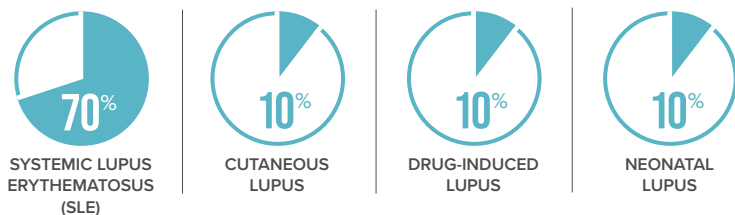
Women who have lupus are at a greater risk of developing:

- Other autoimmune diseases or chronic health conditions
- Lupus nephritis (complications of lupus that result in kidney damage)
- Preeclampsia and other pregnancy complications
- Certain cancers (this is particularly true for those taking immunosuppressants)

The risk can also be related to the weathering of health. For example, factors like stress in childhood, anxiety, depression, and PTSD are associated with the development of lupus.

It is important to note that the exact cause of lupus is unknown and depends on several genetic and environmental factors.

Percentage of Lupus Cases by Type in the United States



Lupus (SLE) is two to three times more prevalent among African American, Hispanic and Latina, Asian American, Native American, Alaska Native, Native Hawaiian and other Pacific Islander women than white women. Research shows that 1 in 250 young African American women have lupus.

Compared to white women, African American women living with lupus have more organs impacted, more active disease, and lower levels of social support. Women from racial and ethnic minority groups tend to be diagnosed with lupus at a younger age and have more serious complications and higher mortality rates.

Lupus is often misdiagnosed because symptoms are similar to other rheumatic diseases, tend to develop and change over time, and there is no single diagnostic test.

Barriers to Care/Access

- Delay in diagnosis (studies have shown it can take an average of four years and four to five health care specialist appointments to diagnose lupus)
- High out-of-pocket costs
- Insurance denial for treatment
- Lack of physician education
- Long appointment and specialist referral wait times
- Misdiagnosis
 - There is no single diagnostic test
 - Symptoms change over time
 - Symptoms mimic those of other rheumatic diseases and diseases like fibromyalgia, rosacea, and other skin conditions
- Physician shortages in rural communities
- Siloed care systems

Caregivers

Caregivers play a critical role in improving the quality of life for an individual living with lupus. They support in assisting with personal care, managing medication, guiding appointments by engaging in dialogue with providers, and utilizing available resources to promote the best health outcomes for their loved ones.

Caregivers face a range of challenges and report an increase in stress levels and a decrease in socialization and paid work time and productivity when caring for someone with lupus. The symptoms of lupus change over time and, as such, the level of support needed at the onset of the disease can change significantly as the person living with the condition ages or as symptoms progress.



Economic Impact

- A 2016 study published in *Nature Reviews Rheumatology* found that the average annual direct health care costs of a person with lupus was **\$33,223**.
- The same study determined that the average annual productivity cost (lost hours of economic productivity due to lupus) was between **\$1,252 and \$20,046**.
- The average annual total costs for people with lupus (combining direct and indirect costs) can be as high as **\$50,000**. These estimates may be higher among people with lupus nephritis and for those with more severe or active lupus.
- A Lupus Foundation of America survey found:
 - **55%** of lupus patients reported a complete or partial loss of their income because they are no longer able to work full-time due to complications of lupus.
 - **1 in 3** people living with lupus have been temporarily disabled by the disease, and **1 in 4** currently receive disability payments.
 - **1 in 4** patients receive their health care through a government-sponsored program, such as Medicare or Medicaid.

HEALTH EQUITY ROADMAP

The Society for Women's Health Research (SWHR) Women's Health Equity Initiative road map features U.S. data on the disproportionate impact of five diseases on women's health based on race and ethnicity, geography, age, and role as a caregiver. SWHR plans to include additional disease states, life stages and issues in this map in the future. Download the fact sheets for more information:

www.swhr.org/healthequity



**WOMEN'S HEALTH
EQUITY INITIATIVE**



Society for
Women's Health Research

[Alzheimer's Disease](#)

[Maternal Health](#)

[Bone Health](#)

[Menopause](#)

[Lupus](#)

[Uterine Health](#)

References

Lupus News Today. Statistics Everyone Should Know About Lupus.
<https://lupusnewstoday.com/social-clips/statistics-everyone-know-lupus/>

The Centers for Disease Control and Prevention Systemic Erythematosus Lupus (SLE).
<https://www.cdc.gov/lupus/facts/detailed.html>

Us in Lupus
<https://www.usinlupus.com/symptoms-in-depth/>

Overview of Cutaneous Lupus Erythematosus
<https://www.uptodate.com/contents/overview-of-cutaneous-lupus-erythematosus>

The Lupus Foundation of America. Understanding Lupus.
<https://www.lupus.org/understanding-lupus>

Society for Women's Health Research, Embracing Life with Lupus: Understanding Gaps and Accelerating Opportunities to Advance the Health of Women with Lupus.
<https://swhr.org/embracing-life-with-lupus-understanding-gaps-and-accelerating-opportunities-to-advance-the-health-of-women-with-lupus/>

The Weathering Hypothesis as an explanation for racial disparities in health: a systematic review
<https://pubmed.ncbi.nlm.nih.gov/30987864/>

The Lupus Initiative: Patients and Supporters.
<https://thelupusinitiative.org/patients-caregivers/>

PR News Wire
<https://www.prnewswire.com/news-releases/new-research-shows-top-barriers-to-lupus-care-and-diagnosis-including-delayed-access-to-specialists-and-high-increased-health-care-costs-301424420.html>