

Lupus facts and statistics

How common is lupus and who does it affect?

- The Lupus Foundation of America estimates that 1.5 million Americans, and at least five million people worldwide, have a **form** of lupus.^[1]
- Lupus strikes mostly women of childbearing age. However, men, children, and teenagers develop lupus, too.
- Ninety percent (90%) of people living with lupus are women. Most people with lupus develop the disease between the ages of 15-44.^[2]
- People with lupus can experience significant symptoms, such as pain, extreme fatigue, hair loss, cognitive issues, and physical impairments that affect every facet of their lives. Many suffer from cardiovascular disease, strokes, disfiguring rashes, and painful joints. For others, there may be no visible symptoms.
- Our best estimate based on available data on incidence is 16,000 new cases per year. The Centers for Disease Control and Prevention (CDC) are **currently gathering updated data** for all ethnic sub-populations in the US, so we anticipate this number will change. The fact remains that lupus is a devastating and life-changing disease that currently has no cure.

9 out of 10

Adults with lupus are women

1 in 3

Lupus patients suffer from multiple autoimmune diseases

What are the 4 different forms of lupus?

- **Systemic lupus** accounts for approximately 70 percent of all cases of lupus. In approximately half of these cases, a major organ or tissue in the body, such as the **heart, lungs, kidneys, or brain** will be affected.^[2]
- **Cutaneous lupus** (affecting only the skin) accounts for approximately 10 percent of all lupus cases.^[2]

- **Drug-induced lupus** accounts for about 10 percent of all lupus cases and is caused by high doses of certain medications. The symptoms of drug induced lupus are similar to systemic lupus; however, symptoms usually subside when the medications are discontinued.^[2]
- **Neonatal lupus** is a rare condition in which the mother's antibodies **affect the fetus**. At birth, the baby may have a skin rash, liver problems, or low blood cell counts, but these symptoms typically disappear completely after six months with no lasting effects.

What is the impact of health disparities on people with lupus?

Lupus is **two to three times more prevalent among women of color**—African Americans, Hispanics/Latinos, Asians, Native Americans, Alaska Natives, Native Hawaiians and other Pacific Islanders—than among Caucasian women.^[3] Recent **research** indicates that lupus affects 1 in 537 young African American women.

The groundbreaking LUMINA (*Lupus in Minority Populations: Nature vs. Nurture*) study reported that African American lupus patients are more likely to have organ system involvement, more active disease, and lower levels of social support compared with white lupus patients.

A 2014 **study** found that minority women tend to develop lupus at a younger age, experience more serious complications, and have higher mortality rates.

Can people die of lupus?

- It is believed that between 10-15 percent of people with lupus will die prematurely due to complications of lupus.^[3] However, due to improved diagnosis and disease management, most people with the disease will go on to live a normal life span.
- A Lupus Foundation of America funded study found that overall, lupus was among the top 20 leading causes of death in females ages 5-64. Among black and Hispanic women lupus ranked 5th in the 15-24 years, 6th in the 25-34 years, and 8th-9th in the 35-44 years age groups, after excluding the three common external injury causes of death from analysis.^[4]

What are the economic impacts of lupus?

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.^[8]

The study also determined that the average annual productivity cost (lost hours of economic productivity due to lupus) was between \$1,252 and \$20,046.^[8]

The mean annual total costs for people with lupus (combining direct and indirect costs) can be as high as \$50,000.^[7-9] These estimates may be higher among people with lupus nephritis and more severe or active lupus.^[8]

A Lupus Foundation of America membership survey found two of three lupus patients reported a complete or partial loss of their income because they no longer are able to work full time due to complications of lupus. One in three have been temporarily disabled by the disease, and one in four currently receive disability payments.^[1]

This same survey found that one in four patients receive their health care through a government-sponsored program, such as Medicare or Medicaid.^[1]

65%

list chronic pain as the most difficult aspect of lupus

\$50,000

is lost annually by each lupus patient in healthcare and lost productivity

What is the role of genetics in lupus?

- Genes do play a role in the predisposition to the development of lupus. There are dozens of known genetic variants linked to lupus. These genes impact both who gets lupus and how severe it is.
- 20 percent of people with lupus will have a parent or sibling who already has lupus or may develop lupus. About 5 percent of the children born to individuals with lupus will develop the illness.^[2]

Although lupus can develop in people with no family history of lupus, there are likely to be other autoimmune diseases in some family members.^[2]

One of three patients responding to our membership survey reported they had **another autoimmune disease** in addition to lupus, and almost half had a relative with lupus.^[1]

How long does it take to get diagnosed with lupus?

- There are many challenges to reaching a lupus diagnosis. Lupus is known as "the great imitator" because its symptoms mimic many other illnesses. [Lupus symptoms](#) can also be unclear, can come and go, and can change.
- On average, it takes nearly six years for people with lupus to be diagnosed, from the time they first notice their lupus symptoms.^[6]
- A majority (63%) of people with lupus surveyed report being incorrectly diagnosed. Of those reporting incorrect diagnosis, more than half of them (55%) report seeing four or more different healthcare providers for their lupus symptoms before being accurately diagnosed.^[6]

What are the biggest burdens of living with lupus?

Responding to our membership survey, most lupus patients reported that they are coping well with lupus (78%), and that other family members are understanding and supportive (72%).^[1]

84% people with lupus name other family members as their primary support network.

Participants cited pain (65%), lifestyle changes (61%), and emotional problems associated with lupus (50%) as the most difficult parts of coping with lupus.^[1]

What is the state of lupus awareness?

- While lupus is a widespread disease, awareness of the disease lags behind many other illnesses. 63% of Americans surveyed have never heard of lupus or know little or nothing about this disease and its symptoms beyond the name indicating there is significant opportunity and need for continued public education.^[11]
- Over half of respondents (61%) believed it takes six months or less for a person to be accurately diagnosed with lupus—significantly underestimating the time it takes to receive an accurate lupus diagnosis.^[11]

Key source documents:

[1] GfK Roper. (2012). Lupus Awareness Survey for the Lupus Foundation of America [Executive Summary Report]. Washington, DC

[2] Pons-Estel GJ, Alarcón GS, Scofield L, Reinlib L, Cooper GS. **Understanding the epidemiology and progression of systemic lupus erythematosus**. Semin Arthritis Rheum. 2010 Feb;39(4):257-68. doi: 10.1016/j.semarthrit.2008.10.007. Epub 2009 Jan 10. Review.

[3] Wallace, D.J., & Hahn, B.H. (2013). Dubois' lupus erythematosus and related syndromes. (8th ed.) Philadelphia, PA: Elsevier Saunders.

[4] Yen E, Singh R. Brief Report: Lupus-An Unrecognized Leading Cause of Death in Young Females: A Population-Based Study Using Nationwide Death Certificates, 2000-2015. Arthritis & Rheumatology. 2018;70(8):1251-1255. doi:10.1002/art.40512

[5] Scofield, L., Reinlib, L., Alarcon, G.S., and Cooper, G.S. (2008). Employment and disability issues in systematic lupus erythematosus: A review. Arthritis & Rheumatism (59)10, 1475-1479. Retrieved from <https://www.womenshealth.gov/p...>

[6] Al Sawah S, Daly RP, Foster S, Naegeli A, Benjamin K., Doll H., Bond G, Moshkovich O, Alarcón G. Understanding Delay in Diagnosis, Access to Care, and Satisfaction with Care in Lupus: Findings from a Cross-Sectional Online Survey in the United States. Presented at the European League Against Rheumatism (EULAR) 2015 Annual Conference. June 2015. Rome, Italy.

[7] Barber, M. and Clarke, A. (2017). Socioeconomic consequences of systemic lupus erythematosus. Current Opinion in Rheumatology, 29(5), pp.480-485.

[8] Carter, E., Barr, S., & Clarke, A. (2016). The global burden of SLE: prevalence, health disparities and socioeconomic impact. Nature Reviews Rheumatology, 12(10), 605-620. doi: 10.1038/nrrheum.2016.137

[9] Meacock, R., Dale, N., & Harrison, M. (2013). The Humanistic and Economic Burden of Systemic Lupus Erythematosus. *Pharmacoeconomics*, 31(1), 49-61. doi: 10.1007/s40273-012-0007-4

[10] Qualtrics. Lupus Awareness Survey: April 2019 [Executive Summary]. Washington, DC; 2019. <https://www.lupus.org/news/2019-lupus-awareness-survey-summary>. June 25, 2019.