



Amplifying the Patient Voice

We are small but mighty and march among giants!

Lupus and Allied Diseases Association (LADA) was founded in 1978 and is a national non-profit organization led by individuals with lupus and allied diseases and their loved ones.

We are dedicated to improving access to care and quality of life for those affected by lupus and other diseases of unmet need by:

- Wielding the patient voice as a catalyst to advance innovative advocacy, education, awareness and biomedical research initiatives.
- Promoting patient-centered care, patient-focused research and empowerment programs.
- Fostering collaboration among stakeholders and promoting unity in the community.
- Ensuring that the patient perspective is included and recognized as an equal stakeholder in the healthcare, public policy and regulatory arenas, and across the research continuum.
- Supporting lupus and autoimmune research that will identify causes, advance better diagnostics, and lead to the discovery of superior treatments, and cures.

***Enhancing Lives by Engaging,
Enlightening, Empowering and Elevating
the Lupus and Allied Diseases Community***

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It is our hope that if you have lupus and/or an allied disease that you will become empowered to take control and learn to manage your condition. By developing a strong knowledge of lupus and a reliable support system, you may achieve better outcomes and a greater quality of life. We realize that lupus and allied diseases do not just affect an individual, but also impact family and friends. Know that we are here for you as you and your loved ones continue on your journey.

About Lupus

- Lupus is an extremely complex chronic inflammatory autoimmune disease in which a triggering agent causes the immune system to dysregulate and attack the patient's own tissue affecting virtually any organ system of the body; including the skin, joints, kidney, brain, heart, lungs, blood and blood vessels.
- There is no known cause or cure for lupus.
- Lupus is a leading cause of kidney disease, stroke and premature cardiovascular disease in young women and is highly individualized, extremely volatile, debilitating, life-diminishing, and potentially fatal.
- By the most conservative estimates, there are at least 322,000 Americans with definite or probable lupus. Recent independent surveys have suggested a prevalence as high as 1.5 million.¹
- Lupus affects women 9 times more often than men,² with eighty percent of new cases developing between the ages of 15 and 44 during child-bearing years or prime of life.³
- Ninety percent of those affected are women; however, men and children are also diagnosed with lupus.⁴
- Lupus disproportionately affects women of color in the United States; it is 2 to 3 times more common among African-Americans, Hispanics and Latinos, Asians, and Native Americans.⁵
- Minority women tend to develop lupus at a younger age, experience more serious complications, and have higher mortality rates—up to 3 times the incidence and mortality of Caucasians.⁶
- It is estimated that as many as one in every 250 African American women in America has lupus.⁷
- Lupus is an unpredictable condition in which symptoms come and go (flares) and complications can suddenly arise.
- No single test exists to diagnose lupus, resulting in many patients suffering more serious complications before a diagnosis is reached.
- Fatigue is the most prevalent and incapacitating symptom experienced by about 85 to 92% of people with lupus, resulting in decreased physical and mental function, and 50% of patients rated it as the most disabling symptom.⁸
- Lupus profoundly disrupts working lives as disease onset typically coincides with critical years for education and career advancement.
- Thirty-three percent of people with lupus in the US are on work disability.⁹
- The annual per patient cost to employers, including medical care, work absence and disability, is higher than for other chronic diseases such as diabetes, chronic obstructive pulmonary disease, and heart disease.¹⁰

¹ National Institute of Arthritis and Musculoskeletal and Skin Diseases *National Institutes of Health Action Plan for Lupus Research*, 2015

² Hahn BH, Wallace, DJ The epidemiology of systemic lupus erythematosus. In *Dubois' Lupus Erythematosus* (5th Edition). Philadelphia: Williams & Wilkins, 1997

³ Wallace DJ, *The Lupus Book: A Guide for Patients and Families*. New York: Oxford University Press, 1995

⁴ Hahn, BJ & Wallace DJ, *ibid*,

⁵ National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health. *Strategic Plan for Reducing Health Disparities*. 2006.

⁶ Sacks JJ, Helmick CG, Langmaid G, Snieszek JE, Centers for Disease Control and Prevention, *ibid*.

⁷ Harley JB, Kelly JA. Genetic basis of systemic lupus erythematosus: a review of the unique genetic contributions in African Americans. *Journal of the National Medical Association* 2002;94(8):670-677.

⁸ Zonana-Nacach A, Roseman JM, McGwin G Jr, Friedman AW, Baethge BA, Reveille JD, Alarcon GS. Systemic lupus erythematosus in three ethnic groups. VI: factors associated with fatigue within 5 years of criteria diagnosis. LUMINA Study Group. *LUpus in MInority populations: NAture vs Nurture*. *Lupus*. 2000;14:101–109. doi: 10.1191/096120300678828046.

⁹ Baker K, Pope J. Employment and work disability in systemic lupus erythematosus: a systematic review. *Rheumatology* 2009, 48:281.

¹⁰ Demas KL, Costenbader KH. *Curr Opin Rheumatol*. 2009, 21:102.