

Study pins down number of Americans with most common form of lupus

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Just over 200,000 Americans suffer from systemic lupus erythematosus, or SLE, a condition in which the body's immune system mistakenly attacks its own healthy tissues, especially joints and skin, a new study shows.

Led by a researcher at NYU Grossman School of the Medicine, the study provides the first national estimate of how widespread the autoimmune disease is since the U.S. Centers for Disease Control and Prevention (CDC) set up a half dozen state registries to track the illness more than a decade ago. SLE affects mostly women, can be fatal, and often involves debilitating flare-ups of fatigue and pain that keep nearly half of adult patients from working.

Importantly, the researcher says the report, publishing in the journal *Arthritis and Rheumatology* online Jan. 21, comes statistically close to officially reclassifying the illness as a rare disease, which disproportionately affects mostly American Indian/Alaskan Native, Black, and Hispanic females. The U.S. Rare Diseases Act of 2002 classifies such conditions as those affecting 200,000 or fewer Americans.

Until now, researchers had relied on disease estimates that were larger but unverified.

"Our study potentially redefines systemic lupus erythematosus as a rare disease in the United States and lays the groundwork for where we need

to focus our efforts to reduce the burden of this disease on Americans," says study lead investigator and rheumatologist Peter Izmirly, MD. Izmirly is an associate professor in the Department of Medicine at NYU Langone Health.

Rare-disease classification could, the investigator says, significantly change efforts to study and treat SLE by decreasing the number of study participants needed for testing new treatments and shaping the design of clinical trials needed before seeking regulatory approval. He also says the team's findings could help plan which neighborhoods or population groups need extra medical resources, including specialty rheumatology clinics, to combat SLE.

Current treatments for lupus, he notes, include steroids or other anti-inflammatory and immunosuppressing medications, especially newer biologic drugs, made from living cells, to prevent patients' immune system's attack on their tissues.

For the study, researchers at NYU Langone and elsewhere analyzed records for 5,417 adults and children diagnosed with SLE since 2002 at all of the state registries for the disease, as well as the Indian Native Health Service. They then calculated the number of people with SLE for every gender and ethnic group and applied those demographic numbers to national population statistics from the 2018 U.S. Census. They concluded that among every 100,000 people nationwide, 72.8 had SLE, for a total of 204,295 out of a population of 330 million.

Their calculations also found that nine times more women than men have SLE, the dominant form of lupus. SLE rates were highest among Native American/Alaskan Native females, at 270.6 per 100,000. Black females ranked next, at 230.9 per 100,000, followed by Hispanic females, at 120.7 per 100,000. Similar disparities were seen among males with SLE, with American Indians/Alaskan Natives having the

highest number, at 53.8 per 100,000, and Black males next, at 26.7 per 100,000.

More information: Peter M. Izmirlly et al, Prevalence of Systemic Lupus Erythematosus in the United States: Estimates from a Meta-Analysis of the Centers for Disease Control and Prevention National Lupus Registries, *Arthritis & Rheumatology* (2021). [DOI: 10.1002/art.41632](https://doi.org/10.1002/art.41632)

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