

LUPUS FACTS AND STATISTICS, 2017



Background

Lupus is an autoimmune disease that triggers inflammation in different tissues of the body, causing the body's immune system to attack its own tissues.¹ There are four types of lupus: systemic lupus erythematosus (SLE), cutaneous lupus, drug-induced lupus, and neonatal lupus. SLE is the most prevalent type of lupus. Symptoms of SLE may include butterfly-shaped rashes across the cheeks and the nose, extreme fatigue, skin rashes, fever, pain or swelling in the joints, sun sensitivity, oral ulcers, and arthritis. In addition, the disease can affect many organs including the lungs, heart and kidneys and may induce seizures, hair loss, and blood cell and immunological abnormalities.¹ SLE may often be misdiagnosed, as the signs and symptoms are not specific, and it can mimic other conditions.¹

Lupus is more common in females than in males, and the hormone estrogen plays an important role in both the origin and development of SLE and other autoimmune diseases.² Many women experience increased lupus symptoms before menstrual periods and/or during pregnancy when estrogen levels are high.³

There are now more than 50 genes that have been found to be associated with lupus, though in most cases, genes alone are not the sole cause of the disease. Lupus can develop in individuals with no family history; however, a family history of other autoimmune diseases is common among individuals with lupus.³

Environmental elements can trigger lupus and exacerbate symptoms. These include ultraviolet rays from the sun and/or fluorescent light bulbs, bacterial infections, colds or viral illnesses, exhaustion, emotional stress, and other events that cause stress to the body such as surgery, physical harm, injury, pregnancy or giving birth, and certain medications.³

National prevalence and incidence estimates for lupus are not available for recent years, as the disease is and not required to be reported, making it difficult to estimate diagnosed cases reliably. Additionally, available estimations vary widely due to different case definitions, small study populations, and varying study methods. A conservative estimate suggests that 161,000 individuals in the U.S. have been confirmed with SLE and as many as 322,000 with a definite or probable diagnosis of the disease. Most people with lupus develop the disease between the ages of 15 to 44 and women and African Americans are the mostly affected groups.¹

Burden of Lupus in Florida

Lupus-related questions were added to the 2018 Florida Behavior Risk Factor Surveillance Survey (BRFSS) questionnaire and the data will be available in late 2019. Until these data are available, the burden of SLE in the state is mainly assessed through the examination of health care utilization records and vital statistics data.

In 2017, in Florida, there were 1,609 emergency department (ED) visits and 1,202 hospitalizations for a total of 982 and 763 patients respectively with SLE listed as the primary diagnosis, and 100 deaths with SLE listed as the underlying cause. Females accounted for a higher proportion of ED visits (n=1,440, 89.5%), hospitalizations (n=1,040, 86.5%), and deaths (n=87, 87.0%) than males (Table 1). The number of SLE-related ED visits and hospitalizations varied broadly by race/ethnicity. While non-Hispanic black residents accounted for only 15.6% of the population, they represented over half of ED visits (53.9%) and hospitalizations (52.2%). However, non-Hispanic whites accounted for the highest proportion of deaths (46.1%).

Floridians aged 35 to 49 years accounted for the highest proportions of ED visits (n=660, 41.0%) whereas those aged 18 to 34 years old accounted for the highest proportions of hospitalizations (n=531, 44.2%). However, individuals aged 50 years and older accounted for the highest proportion of deaths at 61.0%.

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Table 1. Number of Patients and Counts for Emergency Department Visits (ED), Hospitalizations, and Deaths and Their Respective Percentages for Systemic Lupus Erythematosus, Florida, 2017

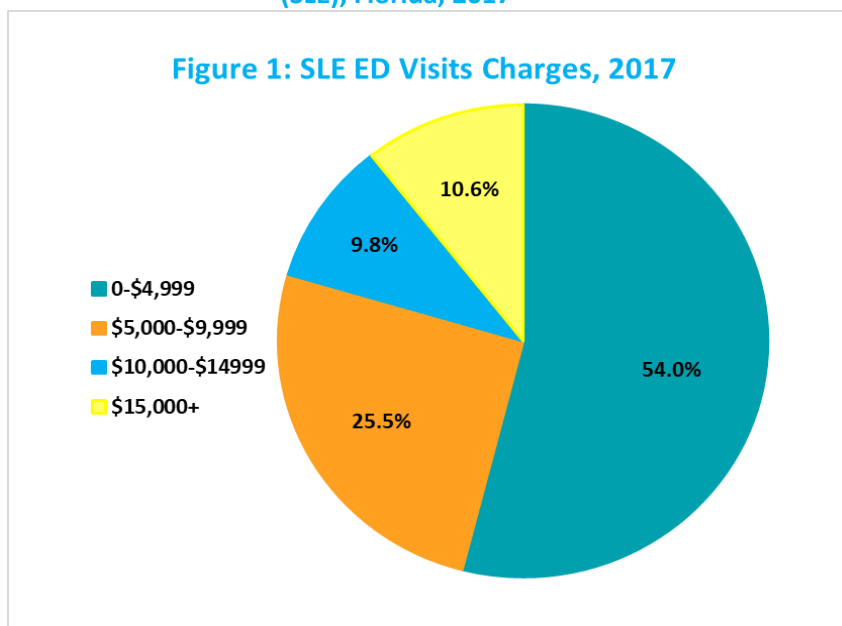
		ED Visits		Hospitalizations		Deaths
		(n= 1,609)	(n= 982)	(n= 1,202)	(n= 763)	(n= 100)
		Count (%)	Number of Patients (%)	Count (%)	Number of Patients (%)	Count (%)
Gender	Male	169 (10.5)	70 (7.1)	162(13.5)	100 (13.1)	13 (13.0)
	Female	1440 (89.5)	912 (92.9)	1040(86.5)	663 (86.9)	87 (87.0)
Race/ Ethnicity	Non-Hispanic White	377 (24.0)	271 (27.9)	224 (19.0)	162 (21.5)	41 (46.1)
	Non-Hispanic Black	846 (53.9)	483 (49.6)	616 (52.2)	383 (50.9)	30 (33.7)
	Hispanic	329 (21.0)	205 (21.1)	280 (23.7)	170 (22.6)	14 (15.7)
	Non-Hispanic Other	18 (1.2)	14 (1.4)	61 (5.2)	37 (4.9)	4 (4.5)
Age Group	0 to 17	40 (2.5)	25 (2.6)	135 (11.2)	49 (6.4)	0 (0.0)
	18 to 34	658 (40.9)	382 (38.9)	531 (44.2)	320 (41.9)	15 (15.0)
	35 to 49	660 (41.0)	387 (39.4)	319 (26.5)	226 (29.6)	24 (24.0)
	50 to 64	217 (13.49)	156 (15.9)	161 (13.4)	118 (15.5)	30 (30.0)
	65+	34 (2.1)	32 (3.3)	56 (4.7)	50 (6.6)	31 (31.0)

Data Sources: Florida Agency for Health Care Administration (AHCA) Ambulatory and Emergency Department Patient Data and Hospital Inpatient Data with M32 (ICD-10-CM code) as primary diagnosis and Florida Vital Statistics records with M32 (ICD-10 code) as the underlying cause of death

Financial Impact of SLE on the Healthcare System in Florida

In 2017, total charges for ED visits for SLE were \$11,503,800 with charges for individual visits ranging from \$0 to \$118,212. Most ED visit charges (54.0%) were less than \$5,000 (Figure 1A), with median charge of \$4,563.

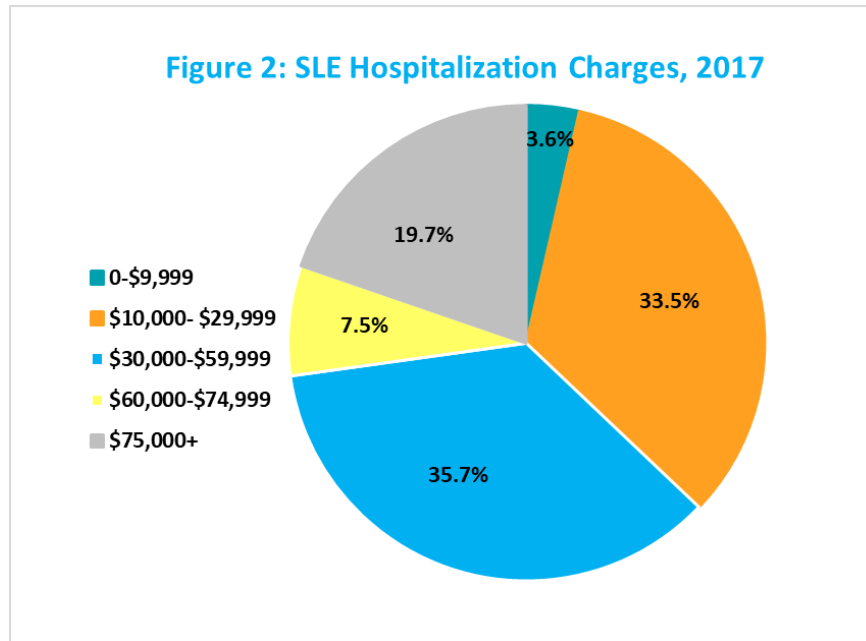
Figure 1. Range of Charges for Emergency Department Visits per Event for Systemic Lupus Erythematosus (SLE), Florida, 2017



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In 2017, total charges for hospitalizations for SLE reached \$72,417,076 with charges for single hospitalization ranging from a low of \$3,018 to a high of \$1,173,120. Most individual hospitalization charges (69.2%) were between \$10,000 and \$59,999 (Figure 1B), with median charge of \$ 38,726.

Figure 2. Range of Charges for Hospitalizations per Event for Systemic Lupus Erythematosus (SLE), Florida, 2017



Data Source: Florida Agency for Health Care Administration (AHCA) Emergency Department and Hospital Inpatient Discharged Data with M32 (ICD-10-CM code) listed as primary diagnosis.

State Actions to Address Lupus

- On April 6, 2018, the Governor of Florida signed House Bill 1009, Chapter No. 2018 – 157 into law adding lupus as an additional priority area for Closing the Gap grant proposals. This change took effect on July 1, 2018.^{4,5}
- The Florida Department of Health Bureau of Chronic Disease Prevention has been collaborating with Big Bend Rural Health Network on the *2016 – 2021 State Action Plan, Florida Public Health Plan for Addressing Lupus*. This plan was developed to provide strategies to engage the community and ensure that efforts to improve population health to address lupus statewide are being met. https://cdn.ymaws.com/www.chronicdisease.org/resource/resmgr/lupus/lupus_tools/Florida_Lupus_PlanFinal.pdf
- The Florida Department of Health in 2018 published an article honoring Lupus Awareness Month in May and is disseminating infographics and other resources to increase awareness and educate Floridians about this disease. <http://www.floridahealth.gov/diseases-and-conditions/lupus/index.html>

References

1. Centers for Disease Control and Prevention (CDC). Systemic lupus erythematosus (SLE). Retrieved February 12, 2019, from: <https://www.cdc.gov/lupus/facts/detailed.html>

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2. Ostensen M. Sex hormones and pregnancy in rheumatoid arthritis and systemic lupus erythematosus. *Ann N Y Acad Sci* 1999;897:131-143
3. Lupus Foundation of America. What causes lupus? Retrieved February 12, 2019, from: <https://resources.lupus.org/entry/what-causes-lupus>
4. The Florida Senate. HB 1009: Closing Gap Grant Program. Retrieved February 14, 2019, from: <https://www.flsenate.gov/Session/Bill/2018/1009>
5. Section 381.7355,(2)a Florida Statutes