

Delayed CDC Lyme Final Lyme Case Numbers for 2019 Finally Released



Lyme Disease Association (LDA) Announces CDC's 2019 Final Lyme Disease Reported Case Numbers: The Centers for Disease Control & Prevention (CDC) has just released the 2019 final Lyme disease reported U.S. case numbers—34,945. CDC reported that cases were ~4% more than in 2018, and the geographic distribution of areas with a high incidence of Lyme appears to be expanding based on data reported to National Notifiable Disease Surveillance System (NNDSS). The number of counties with an incidence of ≥ 10 confirmed cases per 100,000 persons increased from 324 in 2008 to 432 in 2019.

Reporting Delay Explained Final Lyme disease case numbers are usually reported in the fall of the next year (for 2019, should have been reported in 2020). The CDC has responded to LDA inquiries over time that reporting was delayed due to the pandemic and thus to shortages of resources/personnel at many government levels, which was no surprise to anyone following the numbers' delay. CDC also had a note on the reporting page that "Due to the coronavirus disease 2019 (COVID-19) pandemic, data from some jurisdictions may be incomplete."

Past Estimates of Underreporting In the past, CDC has reported that only 10% of cases are actually reported— that translates into 349,450 actual new Lyme cases in the US in

2019. However, in 2021, the CDC announced that “A recently released estimate based on insurance records suggests that each year ~ 476,000 Americans are diagnosed & treated for Lyme disease(1,2). ” Prior Lyme estimates based on claims data had indicated “~300,000 people get Lyme disease each year.” It appears clear from the number of patients culled from insurance data as being diagnosed and treated annually for Lyme disease in the U.S. that cases are vastly under-reported.

1. Schwartz AM, Kugeler KJ, Nelson CA, et al. Use of Commercial Claims Data for Evaluating Trends in Lyme Disease Diagnoses, United States, 2010-2018. *Emerg Infect Dis.* 2021;27(2).
2. Kugeler KJ, Schwartz AM, Delorey M, et al. Estimating the frequency of Lyme disease diagnoses –United States, 2010-2018. *Emerg Infect Dis.* 2021;27(2).

LDA NOTE: The State of Hawaii does not require reporting of Lyme disease. The State of New York estimates the Lyme numbers in many counties and those numbers are not permitted to be entered into CDC reported case numbers. Massachusetts changed their reporting system and their numbers on paper have dramatically dropped in the past few years, moving them out of the top 15 states. To see more states that have changed reporting of Lyme disease over time see **LDA Lyme Cases Map Page**

Top 15 States The LDA has ranked the top 15 states based on the CDC total reported Lyme case numbers for 2019 below. This ranking should not be construed to mean that other states do not have reported Lyme cases. They do have reported cases, Click here for all states, but often patients cannot get diagnosed and/or treated in states that CDC considers “low incidence” states, because doctors in low incidence states are often either afraid to diagnose Lyme or do not understand that surveillance criteria are not meant as diagnostic criteria. Read about Diagnosis by Geography

LDA State Ranking by Reported CDC Lyme Cases

	State Ranking	Reported Cases	Actual Cases (10x = actual cases)
1	Pennsylvania	8998	89980
2	New York	4243	42430
3	New Jersey	3619	36190
4	Wisconsin	2178	21780
5	Maine	2167	21670
6	New Hampshire	1710	17100
7	Minnesota	1528	15280
8	Maryland	1417	14170
9	Connecticut	1233	12330
10	Virginia	1199	11990
11	Vermont	1064	10640
12	Rhode Island	971	9710
13	West Virginia	885	8850
14	Delaware	641	6410
15	Ohio	467	4670