

Estimating the Incidence of Lyme Borreliosis in England and Wales

According to Public Health England (PHE), England and Wales do not have a problem with Lyme Borreliosis (LB). With an annual incidence of only ~1.73 per 100,000 population, the disease appears to be rare. Even if the maximum of their estimate, which allows for unreported cases, is applied (reported cases x 3), that is still only 5.10 cases per 100k pop. Yet nearby neighbouring countries report many times more cases.

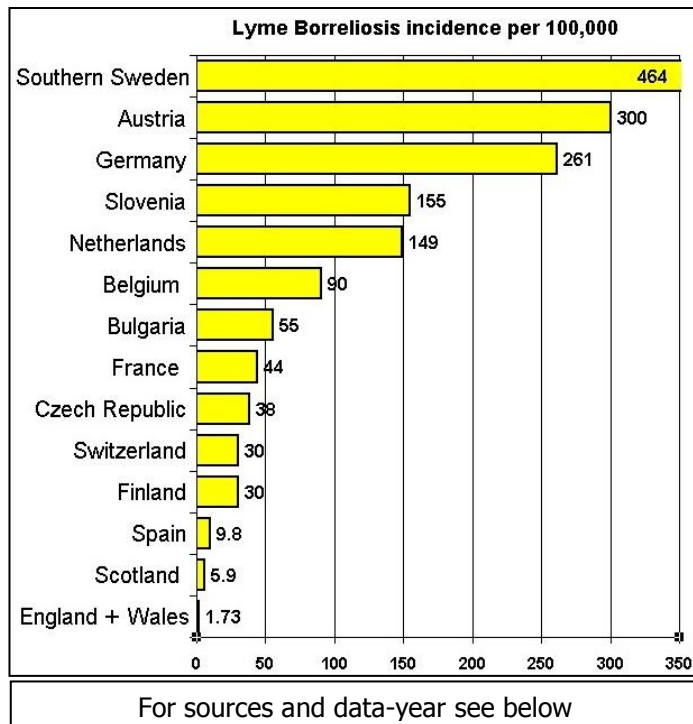
Here are the Lyme borreliosis figures for our nearest neighbours on mainland Europe:

France	44
Netherlands	149
Belgium	90
<i>Average</i>	<i>94 per 100k pop.</i>

Our neighbours are not only geographically close to the UK. They also have large regions with similar climate, geography, animals, birds, insects and ticks.

Pfiefer (2016) observes: "In the Netherlands, rates of people diagnosed with the telltale Lyme rash ranged up to 514 per 100,000 in 2014. In areas of Germany and Sweden, studies of patient records found Lyme rates of 261 to 464 per 100,000. In Europe, the highest national rate—315 per 100,000 in 2009 – has been reported in Slovenia, one of few countries to aggressively track cases."

The following information might help in estimating the true incidence of Lyme borreliosis in England and Wales.



Within a few hundred miles of UK borders (as the tick-infested black bird flies) reported Lyme incidence is many times higher than England and Wales

<1> PHE (2013) record ~1000 cases per annum in England and Wales and estimate that the actual incidence is 2 to 3 times higher than 'confirmed cases' **[2X to 3X]**

<2> In 2007, the late Professor Klaus Kurtenbach of Bath University told the BBC, "In France they have diagnosed 10 times as many cases as here; yet we've found the same number of ticks here carrying the disease." (BBC. 2007) **[10X]**

<3> Dr Darrel Ho-Yen, who was head of the Scottish Lyme Reference Laboratory at Inverness, was quoted in The Field (2005) magazine: "He believes that the known number of proven cases should be multiplied by ten "to take account of wrongly-diagnosed cases, tests giving false results, sufferers who weren't tested, people who are infected but not showing symptoms, failures to notify and infected individuals who don't consult a doctor"." **[10X]**

<4> Bruce Alexander (2012) wrote in the Scotsman, "A recent audit of patients at a Perthshire Medical Practice found a ratio of confirmed cases equivalent to 125 per 100,000 people. Applying this ratio across Scotland, there could be around 6,500 people contracting Lyme disease each year, the vast majority going undiagnosed and untreated." This computes to 30 times the reported incidence for Scotland (2012 data), a country which has 3 times more recorded LB than England and Wales and where more doctors are alert to the risks and symptoms of LB. **[30X]**

<5> The CDC (2013) state: "The new estimate suggests that the total number of people diagnosed with Lyme disease is roughly 10 times higher than the yearly reported number. This new estimate supports studies published in the 1990s indicating that the true number of cases is between 3- and 12-fold higher than the number of reported cases." **[10x]** And CDC (2015) states: "Researchers estimated that 288,000 (range 240,000–444,000) infections occur among patients for whom a laboratory specimen was submitted in 2008", and further add: "...based on medical claims information from a large insurance database. In this study, researchers estimated that 329,000 (range 296,000–376,000) cases of Lyme disease occur annually in the United States." **[>10x]**

<6> In England and Wales, in the 15 years from 1997 to 2011 there were a total of 7,903 cases of LB reported at an average of ~527 cases per annum giving an average annual incidence of ~0.93 per 100k population. (Public Health England. 2013.) This apparent rarity has meant that many doctors are not alert to the risk of the disease, except perhaps for some of those practising in LB 'hot-spots'.

In 2016, patients provided quotes from their doctors which suggest that many UK doctors are not aware of how widespread Lyme borreliosis has become. Here are some examples of what doctors have said to patients:

- Lyme disease does not exist in the UK
- There isn't any Lyme disease in Buckinghamshire. You can only get it in the New Forest and the Lake District in the UK
- In my twenty years of being a GP I have never seen a case of Lyme Disease
- There is no possibility whatsoever that you have Lyme disease, because it's quite rare
- You can't get Lyme disease in Scotland, there aren't even ticks at this time of year
- We don't have Lyme disease in Northamptonshire
- Lyme doesn't exist in Cornwall
- No Lyme or ticks in The South West of England
- UK ticks don't carry Lyme
- You can't have it, it's not like you have been deer hunting in Scotland.
- Well do you have deer in your garden?
- You cannot get Lyme disease in the UK

- The Americans need to keep their diseases to themselves. We don't have Lyme in the UK
- All your symptoms match Lyme. But that's rare
- I don't believe in Lyme
- You've not been out of the UK the child can't have Lyme
- You can't get it in the UK
- You can only get bitten by a tick if you go hill walking.

This suggests that if it is left to doctors to recognise and report cases of Lyme borreliosis, a great many are being missed. Doctors misled by statistics and ill-informed about Lyme could contribute to substantial under-detection and under-reporting. [??X]

<7> The England and Wales Lyme Reference Laboratory at RIPL, Porton Down, is not validated for testing Lyme borreliosis. The tests that they use have not been validated for UK patients or the species and strains of LB borrelia found in the UK. Staff at the reference laboratory at Porton Down and the former HPA reference laboratory at Southampton mistakenly informed doctors and patients that negative tests rule out a Lyme borreliosis diagnosis. PHE's incidence figures do not compensate for the use of unvalidated tests and false-negative results. [??X]

<8> NHS Choices (2015) state: "Some people with Lyme disease also experience flu-like symptoms in the early stages, such as tiredness (fatigue), muscle pain, joint pain, headaches, a high temperature (fever), chills and neck stiffness. More serious symptoms may develop several weeks, months or even years later if Lyme disease is left untreated or is not treated early on."

Infected patients who do not show early symptoms or who have temporary 'flu-like symptoms', could become ill months or years after the initial infection. Unless an EM rash, Bell's Palsy or Acrodermatitis Chronica are amongst those symptoms and recognised, both patient and doctor are unlikely to connect the symptoms with Lyme. This scenario could account for many undiagnosed and misdiagnosed UK Lyme cases. [??X]

<9> VIRAS (2016) surveyed M.E., CFS and Lyme patients using the Isabel Symptom Checker (<http://symptomchecker.isabelhealthcare.com/>). For respondents diagnosed with M.E., the symptom checker suggested a diagnosis of Lyme disease for 83% (n=30). For 22 of these respondents Lyme was in the top 3 suggested diagnoses.

In spite of this substantial overlap in symptoms, VIRAS are not aware of any M.E. or CFS patient, ever being offered investigation for Lyme as the cause of their illness. The reverse is true. PHE re-diagnose Lyme patients with chronic symptoms as CFS and do not recognise chronic Lyme borreliosis. [??X]

CONCLUSION

The true incidence of Lyme in England and Wales will never be known until testing is reliable, doctors are alert to the risk of Lyme, and patients consult a physician for symptoms correlating to Lyme. Considering the above points, the annual incidence of Lyme borreliosis in England and Wales is probably between 15,000 and 30,000.

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