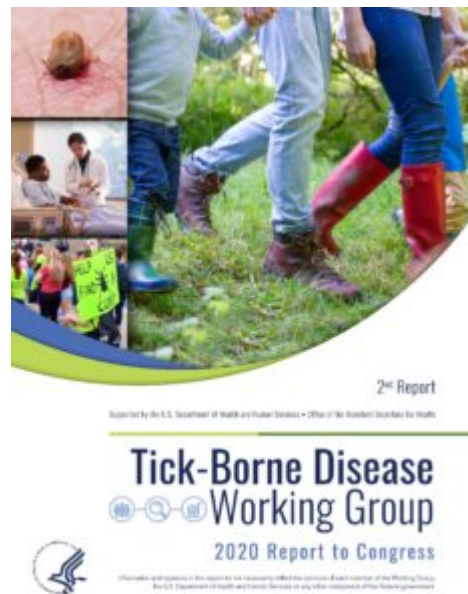


# Government Refuses to Address Geographic Boundary Restriction Preventing Lyme Diagnosis

## How this happened on the Working Group

The Access to Care Subcommittee unanimously recommended the Potential Action below.



## *Working Group Access to Care Subcommittee Report*

**Potential Action 4:** Recommend that CDC provide input to the Council of State and Territorial Epidemiologists, CSTE, that the Lyme disease surveillance case definition be revised such that it abandons the use of geographic parameters for Lyme disease.

The above potential action was altered and removed from Access Chapter to the Surveillance Chapter without any sustainable reason given by the WG agencies for not supporting it. The below change was accepted and voted on by the WG. Pat Smith voted no to the change.

## *Tick-Borne Disease Working Group 2020 Report to Congress*

**Chapter 8 Recommendation:** Recommend that CDC work with Council of State and Territorial Epidemiologists, CSTE, to streamline the surveillance process and reduce the burden on

*clinicians and public health departments by permitting direct laboratory reporting of positive cases.*

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### **How Pat Smith Countered the action**

By virtue of voting no, Pat Smith was able to insert a Minority Response. She developed the following minority response, which can be found in the *Tick-Borne Disease Working Group 2020 Report to Congress*, pp.91, 92

### **Minority Response: Effect of Geographic Restrictions on Lyme Diagnosis**

Access to care, as defined by the National Academy of Medicine, is “the timely use of medical care to obtain the best possible outcome.” With regard to Lyme disease, the Training, Education, Access to Care, and Reimbursement Subcommittee was concerned that additional geographic restrictions added to the surveillance case definition in 2017, have lulled clinicians in “low-incidence” states into mistakenly discounting a potential Lyme disease diagnosis. The resultant diagnostic and therapeutic delays that patients in those states have already reported have subsequently limited their ability to obtain their best possible outcome. To reduce this diagnostic hurdle, the subcommittee recommended that “CDC provide input to the Council of State and Territorial Epidemiologists, CSTE, that the Lyme disease surveillance case definition be revised such that it abandons the use of geographic parameters for Lyme disease” and that “CDC, NIH, and other government agency websites, brochures, and educational materials abandon the use of geographic parameters for the diagnosis of Lyme disease and inform clinicians and the public that Lyme disease has been reported in all states” (Training, Education, Access to Care, and Reimbursement Subcommittee, 2020). This Minority Report specifies why the geographic proviso should not have been removed from the Working Group report as a recommendation to Congress.

In moving to a state-based designation, the surveillance case definition has misled clinicians regarding the risk of Lyme disease in their area. Lyme disease exposure is largely driven by geographical terrain and climatic factors. Because these elements vary within a state, state-based incidence definitions obscure the risk for patients exposed in localized "hot spots." As detailed in the subcommittee's report, outside data sources Quest and Fair Health, the latter with a database of 23 billion healthcare insurance claims, show that CDC statistics on low-incidence states are inaccurate (Lee-Lewandrowski, Chen, Branda, Baron, & Kaurman, 2019; McGinty, 2018). Additionally, instituting more stringent requirements for what constitutes a confirmed erythema migrans case in low-incidence states results in undercounting of cases and sets up a self-perpetuating cycle for a low-incidence designation as doctors there often are not diagnosing and treating. They are frequently concerned about the ramifications from medical boards who have sanctioned physicians in some circumstances.

Additionally, when clinicians underestimate their patients' risk of Lyme disease, they may mistakenly discount true cases of the infection and lengthen the time to diagnosis and treatment. Patients misdiagnosed because of geographically-based misconceptions often have to travel to distant states for a willing and knowledgeable clinician and are likely to experience treatment delay, which increases their risk of developing persistent Lyme disease. As noted in the subcommittee's report, a survey of patients with persistent Lyme disease documented that 70% reported substantial diagnostic delays (Johnson, Shapiro, & Mankoff, 2018). Diagnostic delays can be costly; the total averaged cost of treating late Lyme disease is approximately \$24,000 per year, which is 12 times higher than the cost of treating early Lyme disease (Johnson, 2019; Zhang et al., 2006). The report also details the substantial 92 consequences that persistent Lyme disease has on patients' lives: 72% of patients with chronic

Lyme disease reported their health status as fair or poor and 75% experienced severe or very severe symptoms; many are unable to regularly attend school or hold down a job (Johnson, Wilcox, Mankoff, & Stricker, 2014).

Given the negative impacts on access to care for Lyme disease that geographic parameters in the surveillance case definition impose on clinicians and patients, the subcommittee's initial recommendation on CDC recommending review of the geographic diagnostic restrictions should have remained intact. **Patricia V. Smith, BA**

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