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June 19, 2007

Dear Dr. Gerberding,

I am writing on behalf of the Lyme Disease Association (LDA) and the undersigned groups in reference to the Council of State & Territorial Epidemiologists (CSTE) revisions to the National Surveillance Case Definition for Lyme disease proposed by Matthew Carter. Based on the following analysis, we are opposed to CSTE adopting this amendment and are opposed to any potential CDC acceptance of this revision should it be adopted by CSTE.

There are key problems with the 2007 proposed revisions to the National Surveillance Case Definition for Lyme disease. These problems could undermine the CDC's goals of defining the geographic distribution, monitoring disease trends, identifying risk factors for transmission in areas where Lyme disease is newly emerging, and measuring the public health surveillance burden over time.

The proposal raises concerns that the increasing number of Lyme disease cases places a burden on local health departments. Lyme disease has only become a burden because of the increasing numbers of cases. The CDC, with the help of more than 3,000 counties and territories,(1) reports that the number of reported Lyme disease cases nearly doubled since 1991 to more than 23,000 reported cases in 2005.(2) The 2005 actual number of reported cases per county varied from 0 cases in 5 states (Arkansas, Colorado, Mississippi, Nebraska, and Oregon) to 5,565 cases in New York.(2) Thirty-seven of the fifty states had fewer than 100 reported cases of Lyme disease in 2005.(2) The burden on local health departments appears to be high only for the states with the highest Lyme disease burden. In any case, even the amendment author states that "the revised surveillance case definition alone will not decrease the Lyme disease surveillance burden."(4)

The proposed revisions to the surveillance case definition for diagnostic utilization of an *erythema migrans* (EM) rash will worsen existing problems with underreporting Lyme disease. Under the proposed case definition, an EM will not be confirmatory unless there is a known exposure to Lyme disease. Currently, "known exposure" is defined as exposure in a county in which at least two confirmed cases have been previously acquired or in which established populations of a known tick vector are infected with *B. burgdorferi*.(3) The problem is that many counties may never have enough cases of Lyme disease to be considered as an area of known

exposure or may not have the expertise to identify established populations of a known tick vector infected with *B. burgdorferi*. If the EM is not now classified as pathognomonic for Lyme disease, a county may feel a false sense of security and never assess tick populations for infection rates. Emerging areas of Lyme disease will go unrecognized.

The proposed revisions to require laboratory confirmation of a case of an *erythema migrans* rash in areas where there is no known exposure could also further worsen the underreporting of Lyme disease. The definitions of a qualified laboratory assay is a “(1) a positive culture for *Borrelia burgdorferi*, (2) two-tier testing interpreted using established criteria [1], or (3) single-tier IgG immunoblot seropositivity interpreted using established criteria.”(4) Most Lyme disease patients presenting with an EM rash are now treated without the need for a culture or laboratory tests. Even if laboratory tests are available, antibodies take weeks to reach detectable levels,(5) and early antibiotic treatment can abrogate immune response. (6) To reiterate, the requirement for laboratory confirmation may cause emerging areas of Lyme disease to go unrecognized and may cause people with early disease to progress to disseminated infection.

While the proposed revisions have incorporated the much-needed **probable** and **suspected** case definitions, the proposed definitions need to be further expanded to ensure they do not contribute to the underreporting problem. For the first time, important clinical presentations including neurologic(7) and psychiatric manifestations(8) can be included in the **probable** cases of Lyme disease. Unfortunately, the number of cases of Lyme disease meeting the probable case definition will be underreported when requiring laboratory evidence for this category. The numbers of Lyme disease patients who will fail to be confirmed by the two-tier testing or single-tier IgG immunoblot testing will remain unknown under the proposed definition of probable cases.

The proposed amendment limits the reporting to CDC to **confirmed** and **probable** cases only, further complicating the underreporting problems. Often, the positive laboratory report is the only information available on Lyme disease cases. In Connecticut, for example, only 25% of physicians who had made a diagnosis of Lyme disease reported a case.(9) The CDC could report the numbers of cases of positive laboratory tests for Lyme disease as a sentinel indicator for cases of Lyme disease in emerging areas.

The proposal to include “a single-tier IgG immunoblot seropositivity interpreted using established criteria” test is a welcome start to expanding the laboratory testing criteria.(4) Unfortunately, the sensitivity of the IgG immunoblot is worse than first described in proficiency testing.(10) A proposal to require any laboratory confirmation is weakened when examining the reliability of laboratory testing for Lyme disease.

In conclusion, the proposed revision on the one hand improves the current system by permitting the reporting of confirmed and probable cases; on the other hand, it dilutes **confirmed** cases by restricting the use of EM in diagnosis, which will lead to many current **confirmed** cases reclassified as **probable** and lead to many cases in the south and west never being reportable. An opportunity exists to encourage states to improve surveillance; however, the amendment does not go far enough in encouraging states to track cases not meeting the already narrow CDC surveillance case definition. The new restrictions on the definition of *erythema migrans* will increase underreporting. Underreporting will affect the perception of risk both by the public and by government. It may lead to increased incidence through failure of states to allocate resources towards a problem they think is minor and through failure of the federal government to fund a disease whose numbers appear limited. Therefore, this proposal may worsen the surveillance for Lyme disease rather than giving “public health officials a more complete measure of the surveillance burden that can be used to guide the allocation of scarce public health resources.” A proposal of such significance to public health will be more beneficial when implemented after more thorough research and additional discussion.

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End Notes

1. [http://en.wikipedia.org/wiki/County_\(United_States\)](http://en.wikipedia.org/wiki/County_(United_States)). Accessed June 13, 2007.
2. http://www.cdc.gov/ncidod/dvbid/lyme/ld_rptdLymeCasesbyState.htm. Accessed June 13, 2007.
3. **Orloski KA, Hayes EB, Campbell GL, Dennis DT.** Surveillance for Lyme disease-- United States, 1992-1998. *MMWR CDC Surveill Summ.* 2000;49(3):1-11.
4. Proposed revisions to the National Surveillance Case Definition for Lyme disease, June 2007.
5. **Schutzer SE, Coyle PK, Dunn JJ, Luft BJ, Brunner M.** Early and specific antibody response to OspA in Lyme Disease. *J Clin Invest.* 1994;94(1):454-7.
6. **Dattwyler RJ, Volkman DJ, Luft BJ, Halperin JJ, Thomas J, Golightly MG.** Seronegative Lyme disease. Dissociation of specific T- and B-lymphocyte responses to *Borrelia burgdorferi*. *N Engl J Med.* 1988;319(22):1441-6.
7. **Logigian EL, Kaplan RF, Steere AC.** Chronic neurologic manifestations of Lyme disease. *N Engl J Med.* 1990;323(21):1438-44.
8. **Fallon BA, Nields JA.** Lyme disease: a neuropsychiatric illness. *Am J Psychiatry.* 1994;151(11):1571-83.
9. **Meek JI, Roberts CL, Smith EV, Jr., Cartter ML.** Underreporting of Lyme disease by Connecticut physicians, 1992. *J Public Health Manag Pract.* 1996;2(4):61-5.
10. **Aguero-Rosenfeld ME, Wang G, Schwartz I, Wormser GP.** Diagnosis of Lyme borreliosis. *Clin Microbiol Rev.* 2005;18(3):484-509.

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