

On 6/22/07 4:38 PM, "lymeproject@aol.com"
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We would like to address some issues that have been circulating on the internet.

As we stated in our letter to the CDC and CSTE, we wish to review our concerns with proposed revisions to the National Surveillance Case Definition for Lyme disease. Matthew L. Cartter, MD, MPH, Epidemiology Program Coordinator Connecticut Department of Public Health will propose revisions to National Surveillance Case Definition for Lyme disease on June 27, 2007.

Strengths of the proposed revisions:

The proposed revisions have incorporated the much-needed probable and suspected case definitions. The proposed revision expands the laboratory testing criteria to include "a single-tier IgG immunoblot seropositivity interpreted using established criteria"

Weaknesses of the proposed revisions:

1. Currently all EM rashes are considered to be Lyme disease. Under the CSTE proposal, EM cases with known exposure will count. But EM cases with no known exposure will require a positive test. Endemic is defined as at least two confirmed cases which have been previously acquired or in which established populations of a known tick vector are infected with *B. burgdorferi*. How will this effect counting and patients if the CDC adopts this definition for EM rashes?

a) EM cases in non-endemic counties will no longer be counted as reportable cases by the CDC unless they are confirmed with a positive test. Many counties have not been classified as endemic. Therefore, people in those counties who develop an EM rash without a positive test might not be treated and would not be counted.

b) If a doctor decides to treat an EM in a non-endemic county, the treatment may prevent the development of a positive blood test which is required for the case to be counted, therefore the case will not be counted.

c) Furthermore, late manifestations defined as Bell's palsy, arthritis, lymphocytic meningitis, and high grade heart block will not be reported to the CDC without strict laboratory confirmation in both endemic and non-endemic counties.

In any scenario we are losing case numbers (state numbers will decrease as well as national numbers), preventing the establishment of the disease in non-endemic areas, patients may not receive treatment and insurance companies will have another tool to refuse payment.

The definition of a probable case of Lyme disease is too restrictive. It precludes any other case of physician diagnosed Lyme without evidence of laboratory infection. The numbers of physician diagnosed cases of Lyme disease including neurologic and psychiatric manifestations cannot be estimated if they cannot be confirmed using strict laboratory criteria.

The suspected cases category undermines the value of mandatory laboratory reporting. States could easily comply their mandatory laboratory requirement without ever contacting a physician merely by reporting all such cases as suspected. Previously State DPH had to check with physicians to qualify positive cases before reporting them to the CDC. There is no provision for reporting suspected cases nor releasing the data for suspected cases unless a data sharing agreement is signed. Instead, the revisions explicitly state that "states and territories will send CDC case data for all confirmed and probable cases. Only fully deidentified case data will be released by CDC to the general public. Other releases require signed data sharing agreements using a format pre-approved by the state/territorial health agency."

Consequences of the proposed revisions:

The surveillance system for Lyme disease varies for each county and state. Connecticut's decision to abandon mandatory reporting in 2003 is an example of the consequences of a state changing its surveillance system. The number of cases of Lyme disease in Connecticut dropped by 70% merely by changing the state's surveillance system. In contrast to Connecticut, California Lyme disease cases have quintupled since mandatory lab reporting was instituted in September 2005. Some counties and states may have already chosen not to report Lyme disease cases unless Lyme disease is endemic to the county.

If so, emerging areas for Lyme disease will remain unrecognized. The suggestion that some counties or states may already have restrictive surveillance systems for Lyme disease should not justify the more restrictive revisions in the National Surveillance Case Definition. The proposed revisions could worsen the problems of underreporting. Additionally, the perceived risk of acquiring Lyme would be diminished for physicians, the public, and the government.

In summary, a proposal of such significance to public health would be more beneficial when implemented after more thorough research and additional discussion.

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