



## Wisconsin Division of Public Health (DPH) Recommendation for a Sustainable Lyme Disease Surveillance System

### Background:

The first documented case of erythema migrans (EM) in North America was diagnosed in a Wisconsin grouse hunter in 1969<sup>1</sup>. Following the recognition of Lyme disease as an emerging tickborne zoonosis in the northeastern United States during the mid-1970s, and identification of the infectious agent *Borellia burgdorferi* in 1982, a Midwestern focus of Lyme disease was confirmed in Wisconsin and Minnesota. Lyme disease was added to Wisconsin's reportable disease list in 1980 and to the national list of reportable diseases in 1991.

Surveillance of reported cases has enabled public health officials to track the emergence of Lyme disease from a novel infection to what is now the most commonly reported vectorborne disease in the United States. Neither past nor current surveillance capture every diagnosed case of Lyme disease. In one study conducted in the area of Wisconsin served by the Marshfield clinic, only one third of probable Lyme disease cases during 1992-1998 were captured by the state surveillance system<sup>2</sup>. Nevertheless surveillance data have been essential for describing the seasonality of the disease and the age-groups and geographic areas at greatest risk. In Wisconsin, human case surveillance data along with tick surveys have documented the steady spread of Lyme disease from the northwestern corner of the state to the east and south.

Throughout the 1990s, Lyme disease incidence in Wisconsin was relatively stable, averaging 440 confirmed cases reported annually. The reported incidence increased markedly during the 2000s, reaching 3,520 confirmed and probable cases in 2010. Much of this increase is real, attributed to the expanding geographic range of the *Ixodes scapularis* tick. Other contributing factors include the expanded Council of State and Territorial Epidemiologists (CSTE) and Centers for Disease Control and Prevention (CDC) 2007 case definition introduced in 2008 to capture probable cases, the implementation of the Wisconsin Electronic Disease Surveillance System (WEDSS), and the electronic laboratory reporting (ELR) system. Prior to WEDSS/ELR, paper laboratory reports with missing clinical information were often shredded. Today most of these reports are received via ELR into the WEDSS staging area, requiring processing by local or state public health officials and follow-up with laboratories and healthcare providers to obtain missing demographic and clinical information. During 2010, a total of 6,758 Lyme disease incidence reports were received into WEDSS, of which 2,527 were classified as confirmed, 993 as probable, 742 as suspect, and 2,596 as not a case.

Currently, complete follow-up of a reported case of Lyme disease may require local health department (LHD) staff or state officials to make up to four phone calls:

- Call to reporting facility (lab, medical records, IP, etc) to obtain missing patient address to determine what jurisdiction the case should be assigned to

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<sup>1</sup> Scrimanti RJ. Erythema chronicum migrans. Arch Dermatol 1970;102:104-5.

<sup>2</sup> Naleway AL, Belongia EA, Kazmierczak JJ et al. Lyme disease incidence in Wisconsin: a comparison of state-reported rates and rates from a population-based cohort. Am J Epidemiology 2002;155:1120-7

- Call to laboratory for missing lab results (mostly for EIA results required to meet laboratory surveillance criteria)
- Contact hospital infection preventionist (IP), nurse or other healthcare provider to obtain clinical information including date of illness onset, signs and symptoms (eg., physician-diagnosed erythema migrans (EM), arthritis, Bells palsy, carditis and other).
- Follow-up with patient to provide education regarding Lyme disease prevention and control.

Lyme disease case reporting is also a significant burden for healthcare providers. Currently providers are asked to provide clinical information for all positive lab tests reported from their facility, even though some test results may not meet laboratory criteria. This is done to identify cases of physician-diagnosed EM, which are considered confirmed regardless of lab results. For providers in high Lyme disease incidence areas, particularly those who enter information directly into WEDSS, the time required to provide this information is significant. It can take ~20-30 minutes for each patient to be entered into WEDSS. Many IPs have reported that their facility has only 1-2 IPs to cover all reportable conditions and they are often 4-5 months behind in reporting. Lyme disease reporting competes directly with reporting of other diseases of greater public health significance, including sexually transmitted infections, tuberculosis and emerging tickborne infections such as anaplasmosis, babesiosis and ehrlichiosis. Providers question why so much of their time should be dedicated to Lyme disease surveillance.

DPH staff review all Lyme disease reports in WEDSS that are “Sent to state.” Case status is assigned according to the CDC/CSTE national case definition and each report is finalized. A full-time vectorborne epidemiologist oversees the DPH Lyme disease surveillance and though not funded specifically for Lyme disease spends significant time reviewing cases, developing surveillance protocols, training LHD staff and representing DPH on Lyme disease issues. The DPH has only one 0.5 FTE research analyst funded specifically for Lyme disease. In recent years the DPH has managed the huge volume of reported Lyme disease cases by recruiting part-time students, both paid and unpaid, to help with the review and close-out of cases.

The burden of Lyme disease surveillance falls disproportionately on Wisconsin’s Western and Northern public health regions. In December 2011, LHD directors from the Western Region invited DPH staff to attend their regional Wisconsin Association of Local Health Departments and Boards (WALHDAB) meeting to discuss Lyme disease surveillance. They made the following points:

- Lyme disease surveillance is not sustainable using current methods, particularly in high incidence areas. Lyme disease surveillance is not a good use of limited public health resources, and follow-up is given low priority.
- A policy change is needed at the state or federal level. Some requested that Lyme disease be removed from the list of reportable diseases. Short of that, changes are needed to reduce the workload for local health agencies and healthcare providers as soon as possible, preferably before the next tick season starts.
- The current burden on healthcare providers is undermining the relationship between LHDs and their local providers, jeopardizing other public health activities.

- When asked, the LHD health officers said they would welcome a more centralized surveillance approach if it reduced the workload for LHD staff and providers.

In response to the Western WALDHAB meeting, a DPH Lyme disease surveillance working group was established during the winter of 2011-2012 to develop a more sustainable approach to Lyme disease surveillance. After considering several options the workgroup made the following recommendations:

**Lyme disease surveillance methods recommended by the DPH Lyme disease surveillance working group:**

- Require that healthcare providers report positive laboratory results (similar to current procedure) and only cases with EM rash ( $\geq 5\text{cm}$  and diagnosed by a physician or medical personnel).
- Whether reporting on paper or using WEDSS, healthcare providers need only check the patient has EM rash that meets surveillance criteria. **No other symptoms need to be reported.** This will reduce the need to comb through the medical record looking for symptoms.
- The following CDC-required fields will still be required: patient name, address, age, date of birth, race, ethnicity, gender, and illness onset date.
- Healthcare providers will not be expected to report cases that do not have a physician-diagnosed EM rash  $\geq 5\text{cm}$ .
- LHDs will be expected to review case reports with EM rash.
- LHDs will *not* be expected to review incoming laboratory reports or call providers when a positive laboratory report is received.
- Positive laboratory reports received via ELR will be automatically imported from the staging area into WEDSS and assigned disease as “Lyme Laboratory Report.” Thus, these reports will be available in WEDSS if needed and may be used by DPH to generate more complete estimates of total disease burden.
- In areas of Wisconsin where Lyme disease is just beginning to emerge and where case volume is still low, LHDs that choose to can still monitor incoming “Lyme Laboratory Reports” to track *all* potential confirmed and probable cases, and follow-up with providers to obtain information for cases without EM rash.

**Data supporting application of the new surveillance methods**

To understand the impact of this surveillance change DPH analyzed Lyme disease surveillance data for the period 1991-2011. During this period, the annual proportion of cases with EM was fairly consistent, averaging 65.1% of total reported confirmed cases annually (range 50.5%-75.9%), and statewide trends in the number of cases with EM reported annually were similar to trends in total cases (Figure 1). At the county level, total confirmed cases and cases with EM were highly correlated (Figure 2), and maps of the 3-year average county incidence provide a very similar picture of the spread of Lyme disease across the state, whether based on total confirmed cases or cases with EM only (Figure 3).

During 2010, public health officials at the local or state level conducted follow-up on an estimated 6,852 Lyme disease case reports. Had the proposed methodology been employed during 2010, approximately 1,916 confirmed cases with physician-diagnosed EM would have been identified at the provider level and been entered in WEDSS. Beyond the initial record review for presence of EM, public health would not be required to perform additional surveillance follow-up for 72% of the case reports that didn't identify the confirmatory EM rash.

### **Advantages and disadvantages of the new surveillance methods**

The workgroup identified the following advantages and disadvantages of the proposed EM-only surveillance system:

#### Advantages:

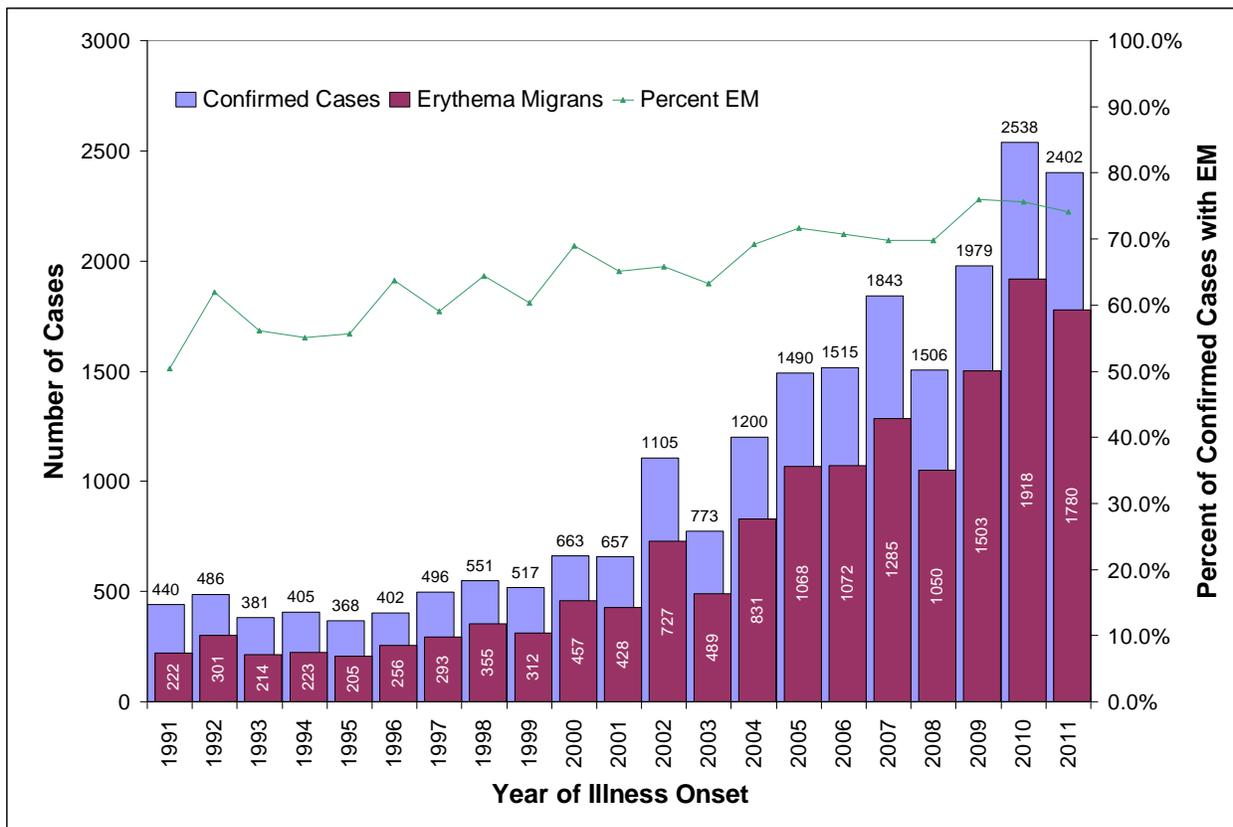
- An estimated 72% reduction in Lyme disease caseload for the public health system.
- An estimated 30-50% reduction in Lyme disease workload for healthcare providers.
- Case reports may be completed in a timelier manner because of the reduced level of detail required for each disease incident.
- The new system will still provide sufficient data to describe general temporal and geographic trends in Lyme disease occurrence throughout Wisconsin, including the ongoing emergence of Lyme disease in southern and eastern Wisconsin.
- The distribution of signs and symptoms among reported case patients has been fairly consistent throughout the years and it is no longer necessary to collect symptom information for the purposes of public health surveillance.
- Wisconsin will be able to report partial numbers (representing only confirmed Lyme disease cases with EM) at a national level. Other states (Connecticut, New York state, and Minnesota) with high Lyme disease incidence are also exploring alternative method of surveillance to reduce burden. New York State has adopted an estimated reporting method in counties with high Lyme disease burden (following up on 20% random reports and multiply by the inverse sampling fraction); however, the estimated numbers are not currently reportable at the national level.
- Public health agencies will be able to redirect limited resources towards higher priority activities, including:
  - Surveillance for other emerging tickborne diseases such as anaplasmosis, ehrlichiosis, and babesiosis.
  - Tickborne disease prevention and control.
  - Prevention and control of other diseases of public health significance, such as tuberculosis and sexually transmitted infections.

#### Disadvantages:

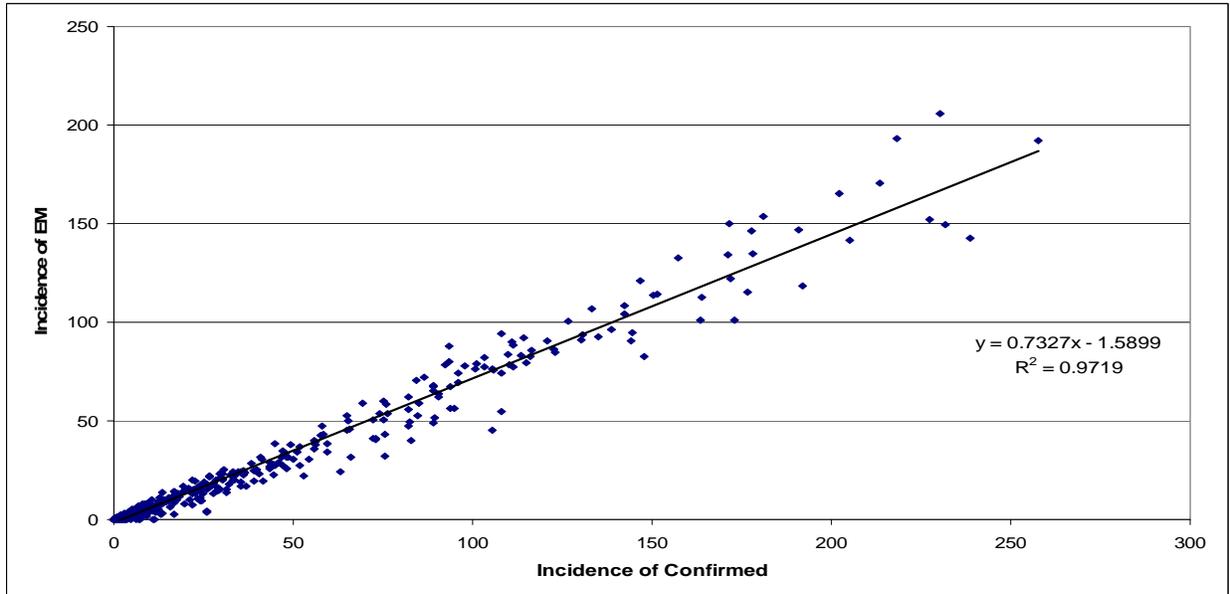
- Loss of non-EM confirmed cases. (During 2010, 613 reported confirmed cases, representing 24.2% of all confirmed cases, did not include EM rash.)
- Loss of probable cases. (During 2010, probable cases accounted for approximately 15% of all reported confirmed and probable cases.)
- Less complete Lyme disease case information in counties where Lyme disease is emerging.

- Less complete reporting to CDC. CDC has tentatively confirmed that Wisconsin data can still be published in the Morbidity and Mortality Weekly Report (MMWR) but may require a footnote to explain that the data represent EM cases only.
- Lyme disease advocacy groups lobbied in support of the expanded 2007 case definition which added probable cases, and may be concerned that this new method will result in fewer reported cases and less attention to Lyme disease.

**Figure 1:** Number of total reported confirmed cases of Lyme disease, cases with erythema migrans (EM) rash, and percent of cases with EM rash, by year, Wisconsin, 1991-2011.



**Figure 2:** Correlation of Lyme disease confirmed cases and EM cases. Data points represent three year average incidence rates for each county during the years 1990 through 2010.



**Figure 3:** Map series of Lyme disease incidence comparing all reported confirmed cases and confirmed cases with EM for select three-year periods, incidence moving across the state.

