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Failures tracking Lyme disease makes a difference

By Yvonne Bokhour and Peter S. Arno

MANY wonder why the White House delayed revealing President Bush's bout with Lyme disease. There's a bigger issue: Was his case submitted to the Centers for Disease Control and Prevention for tracking or did it vanish, like tens of thousands of others?

Although Lyme disease is the most common vector-borne disease in the United States, it's hard to be sure how many people have been infected. The CDC recently announced Lyme cases have doubled since 1991, with 20,000 new cases reported each year. But experts acknowledge Lyme surveillance is limited. The CDC relies on states to report, and each state has its own methods.

Without a comprehensive, consistent system, we cannot know Lyme's true reach.

Lyme is likely to be under-reported. Research suggests official reports represent only 10 percent to 20 percent of diagnosed cases. Recently, reporting methods have come under particular scrutiny in Connecticut, a state with the second highest rate of Lyme disease in the nation.

Unfortunately, Lyme is controversial: nearly every aspect, from diagnosis to treatment, sparks heated debate. Now, apparently, counting cases is also a hot-button issue. If we know Lyme is here, causing problems, why bother tracking every case? What difference does it make?

Economically, at least, quite a lot - about \$300 million in Connecticut alone.

Scientific and humanitarian concerns should drive any discussion of reporting. But sometimes, money talks. Many families are stressed by the financial burden imposed by Lyme disease. What do case reports reveal about patient struggles, in dollars and cents?

Connecticut's reporting system changed drastically in 2003 and with it, our ability to assess Lyme's economic impact. Until then, both doctors and labs were required to notify the state Department of Public Health when patients tested positive for Lyme. That year, 4,631 cases were reported. But in 2003, cases fell to 1,403. Why? The state stopped requiring labs to report them. Trends would still be discernible, officials said, and the state would soon install a computerized system to capture laboratory numbers.

Five years later, this system has yet to be fully implemented. The state asserts technological challenges have prevented its completion - a delay many find unacceptable.

State Attorney General Richard Blumenthal noted: "We have been demanding that the Department of Public Health do more accurate reporting. Awareness of Lyme disease helps people prevent it. If people think that Lyme disease is going away because of under-reporting, it could give them a false sense of security." In addition, accurate case numbers might improve diagnosis, since doctors would know how probable Lyme is in their communities.

In 2006, the CDC published a study of the economic impact of Lyme disease. It concluded the average case generates \$8,172 in costs using year 2000 dollars. Adjusting for inflation, current costs would run \$10,256.

If we apply this amount to Connecticut's case numbers, it's clear accurate reporting provides vital data regarding the epidemic's toll. Connecticut reported 1,788 cases in 2006, mainly from doctors. Using the estimate of \$10,256, these cases would have generated costs of over \$18 million.

But what if labs were still reporting? By assuming that labs report in the same proportion as 2002, we're looking at 5,902 cases, generating costs of more than \$60 million.

Finally, consider this eye-opener: Assuming conservatively that case reports represent 20 percent of diagnosed cases, Connecticut's 2006 case numbers jump to 29,509, generating costs of more than \$300 million.

In a nutshell, here's the difference reporting methods can make: the difference between 1,788 cases and 29,509 cases. The difference between \$18 million and \$300 million. All in one year. All in one state.

Poor reporting methods effectively hide Lyme's health, economic and political impact. Whether visible or not, however, these costs are real to patients and their families. If even half the 29,509 cases were misdiagnosed or overestimated, these calculations offer a truer picture of Lyme's magnitude than official numbers. Moreover, incomplete Connecticut reporting distorts national trends, skewing our understanding of this growing public health threat.

Until researchers resolve numerous dilemmas, patients will fight symptoms affecting not only their personal welfare, but the financial security of their families and the economic fabric of their communities. The entire country needs a comprehensive, accurate and consistent method of reporting to reduce Lyme's serious personal, public health and economic burden. It would seem counting cases makes a very big difference indeed.

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