The Importance of Mandatory Laboratory Reporting in Assessing the Economic Impact of Lyme Disease in Connecticut

Statement

by

Yvonne Bokhour
Master's Candidate
Health Advocacy Program, Sarah Lawrence College
and Co-facilitator
Wilton Lyme Disease Support Group

Before the State of Connecticut General Assembly
Committee on Public Health
Hartford, CT

February 26, 2007

Oral Testimony

Introduction

Good afternoon Madame Chair and members of the Committee. My name is Yvonne Bokhour and I am a graduate student studying Health Advocacy at Sarah Lawrence College. For the past 9 years, I have co-facilitated the Wilton Lyme Disease Support Group. I am here today in support of Bill Number 5747.

More than 700 patients have shared their stories at the Support Group since 1998. Their heartbreak, and my personal encounter with Lyme disease (LD), led me to graduate school. My current research, contained in my written testimony, concerns the economic impact of Lyme disease, particularly the financial hardships imposed by misdiagnosed and under-treated Lyme. This afternoon, I will highlight a few key findings, which provide dramatic support for the importance of accurate reporting.

Over the years, trends have emerged in patient narratives. Most arrive at our group with late-stage Lyme that has advanced due to misdiagnosis or inadequate treatment. Some have been infected more than once. Co-infection is increasingly common. Multiple family members may be stricken together. Patients' lives may be thrown into turmoil by the intensity of their illness. In addition, they may be overcome by financial burdens. Economic ramifications extend beyond individuals to schools, employers, insurers and government.

Accurate case reports are essential to assess Lyme's economic and public health impact. Numerous studies published before and after Connecticut eliminated mandatory lab reporting have demonstrated that official case reports of Lyme disease represent only 10 to 20% of diagnosed cases. [1, 2, 3, 4, 5, 6]

Although Lyme is the most common vector-borne disease in the United States, economic research has been limited. [7, 8] The latest study was published in 2006 by the Centers for Disease Control (CDC). [9] Let's look at their numbers, which provide a pointed glimpse into the importance of accurate case reports. The calculations I will present were made under the direction of Peter S. Arno, Professor of Health Economics at Sarah Lawrence and Director, Division of Public Health & Policy Research in the Department of Epidemiology and Population Health at Montefiore Medical Center.

The CDC calculated that "in general, a LD patient (clinically defined early or late stage) costs $2,970 in direct medical costs plus $5,202 in indirect medical costs, nonmedical costs, and productivity losses." [10] These costs understate those of support group attendees, whose expenses are generally higher. But if we apply these conservative numbers, which total $8,172 per case, to CT case reports in 2005, which total 1,810 cases,[11] the economic impact amounts to nearly $15 million dollars in that year ($14,791,320).

Let us take our calculations a step further. If we assume the official number of case reports in 2005, or 1,810, represents 15% of diagnosed cases (a conservative mid-range estimate) the total number of diagnosed Lyme disease cases in 2005 would have been 12,067 not 1,810. If we multiply the costs per case ($8,172) by the total number of cases (12,067), the economic impact jumps to nearly $99 million dollars ($98,608,800). The difference in economic terms between roughly 1,800 cases and 12,000 cases is nearly $84 million dollars. It would be even higher if we took inflation into account. And of course, the 1,800 cases officially listed are much less than they would have been had labs been reporting. In fact, let's use the same approach to assess 2002, the last year before mandatory lab reporting was eliminated. If we again assume official case numbers represent 15% of diagnosed cases, the

4,631 cases reported that year[12] really reflect 30,000 (30,873) cases of Lyme in CT. In economic terms this would have generated costs of more than $250 million dollars.

This dramatic economic impact is based on conservative numbers that do not include costs associated with misdiagnosis, under-treatment, repeat infection, co-infection, number of household members affected, insurance claim denials and expenses incurred by employers and schools. It is hidden by poor reporting in general and made worse by the lack of mandatory reporting specifically. The fact that these costs are hidden does not mean they are not real to patients, their families or society at large.

Until researchers resolve numerous diagnostic and treatment dilemmas, patients will continue to battle symptoms that affect not only their personal well-being, but the financial security of their families and the economic fabric of their towns and states. Hundreds of patients seen at the Support Group testify to the importance of accurate reporting and additional economic research. Bill Number 5747 corrects a serious misstep by the State of Connecticut and will help move us forward to more fairly and accurately deal with the Lyme disease epidemic here and across the country.

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[9] Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. "Economic Impact of Lyme disease." *Emerging Infectious Diseases*, 2006; 12 (4):653-660.
[10] Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. "Economic Impact of Lyme disease." *Emerging Infectious Diseases*, 2006; 12 (4):653-660.
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[12] Centers for Disease Control. "Reported Lyme Disease Cases By State, 1993-2005." Available at: http://www.cdc.gov/ncidod/dvbid/lyme/ld_rptdLymeCasesbyState.htm. Accessed 25 Feb 2007.