



False and Misleading Information About Lyme Disease

Recently, there has been considerable interest in the topic of fake news. For infectious diseases physicians, false and misleading information about the diagnosis and treatment of Lyme disease is not new. It is increasing in frequency and prominence, creating much confusion among primary care physicians and their patients.

Persistent, unexplained subjective symptoms such as chronic fatigue and pain are common in the general population. Annual surveys by the Centers for Disease Control and Prevention (CDC) indicate that approximately 15% of women and 10% of men in the US felt either exhausted or extremely tired either every day or most days of the preceding 3 months.¹ The Institute of Medicine reports that acute and unspecified chronic pain affects 116 million Americans, about 30% of the population; such individuals often go from one physician to another, unable to find anyone who can either identify the cause of their pain or suggest a remedy.² Many patients with symptoms attributed to chronic Lyme disease likely come from these groups that share similar symptoms and personal experiences.³ Although there are multiple definitions of chronic Lyme disease,³ we are using the term to refer to patients with persistent, unexplained subjective symptoms, with no documented history of Lyme disease and without credible laboratory evidence – past or present – of infection with *Borrelia burgdorferi*, the bacterium that causes Lyme disease.

Health care providers who diagnose chronic Lyme disease question the reliability of 2-tier antibody-based tests for Lyme disease approved by the Food and Drug

Administration (FDA).⁴ They espouse the viewpoint that the validity of 2-tier testing is “no better than that of a coin toss.”⁵ This ignores well-recognized features of both the disease process and the intrinsic characteristics of antibody-based tests for the diagnosis of Lyme disease. Because it takes several weeks for antibodies to develop, many patients with Lyme disease will be seronegative early in the illness. However, patients who have been infected by *B. burgdorferi* for many weeks or months are almost invariably seropositive by 2-tier tests.⁴ Many patients remain seropositive for months or years after their infection has been cured. Despite such evidence, Lyme disease patient advocates have lobbied state legislatures in both Maryland and Virginia to pass laws that require physicians to inform their patients that a negative result from an FDA-approved diagnostic test does not necessarily mean that they do not have Lyme disease. This casts doubt on the validity of approved diagnostic tests and encourages seronegative patients with chronic nonspecific symptoms to seek treatment for their symptoms with prolonged courses of antibiotics, often at great personal expense and to the detriment of their health.⁶ This occurs despite results of multiple clinical trials that show that patients with well-documented Lyme disease who have residual nonspecific symptoms after treatment do not benefit from additional treatment, even with extended courses of intravenous antibiotics.^{7,8}

It is highly implausible that either patients with chronic Lyme disease or patients who had Lyme disease and have posttreatment symptoms, who are seronegative, who have no objective findings, and who have already been treated extensively with antibiotics would have cultivable *B. burgdorferi* in their blood. Nevertheless, fake research has been used to support this notion. For example, in a report that used a novel culture medium that required Detroit tap water for its formulation, the investigators claimed to have detected live *B. burgdorferi* in the blood of >90% of 47 patients with “chronic Lyme disease,” despite the fact that only 9% were seropositive and that all patients had been previously treated with at least 6 weeks of intravenous antibiotics.⁹ These results could not be confirmed, and subsequent studies showed that this novel culture medium could not support the growth of *B. burgdorferi* in vitro for more than 4 days.^{10,11} Fake blood cultures are not the only false tests that have been used to support a misdiagnosis of

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Lyme disease. It has been reported that the Lyme Urinary Antigen Test gave false-positive results for 10 of 10 normal subjects with no history of Lyme disease.¹² The CDC lists several other types of nonvalidated in-house tests, often used by Lyme disease specialty laboratories, which are not recommended for the diagnosis of Lyme disease.¹³ For example, one Lyme specialty laboratory provides a non-FDA-approved Western blot that is interpreted using criteria other than that proposed by the CDC for standard 2-tier testing; immunoblot testing by this laboratory was found to have a >55% false positivity rate.¹⁴

False and misleading information about Lyme disease is not restricted to fake diagnoses, fake diagnostic tests, or fake laboratory research. One astounding claim is that Lyme disease is sexually transmitted.¹⁵ The CDC has no confirmatory evidence that Lyme disease is sexually transmitted.¹⁶ Furthermore, studies using well-characterized animal models of Lyme disease have found no evidence for sexual transmission.¹⁷

Unfortunately, the news media sensationalizes controversial aspects of patients' stories that they consider "newsworthy" under the guise of increasing "Lyme awareness."¹⁸ Media-sponsored public discussions often use a format based on "false equivalency" in which emotional arguments and unproven opinions are given the same weight as the results of rigorous, evidence-based scientific research; obviously, it is incumbent upon all participants in such discussions to provide sufficient evidence to support the statements and claims they make. It should be noted that Web sites sponsored by the CDC (<https://www.cdc.gov/lyme/index.html>) and the National Institutes of Health (<https://www.niaid.nih.gov/search/niaidsite/Lyme%20Disease>) provide evidence-based information about Lyme disease, whereas many other Internet sites provide misinformation.¹⁹

Politicians are attempting to displace mainstream physicians as diagnosticians in the complex world of Lyme disease by passing legislation that encourages the use of unproven treatments and that requires health insurance companies to pay for unsafe remedies with no documented benefit and well-documented adverse effects. This makes it difficult for medical review boards to safeguard public health by disciplining those who put patients at risk. It also increases the cost of health care without tangible benefits. The real shame in all of this is that the time, attention, and resources that are being misdirected could be better spent on research that is designed to address, to understand, and to try to remedy the problems that these patients have. By so doing, we might begin to improve the lives of those who are genuinely and indisputably suffering — just not from Lyme disease.

Eugene D. Shapiro, MD^a

Phillip J. Baker, PhD^b

Gary P. Wormser, MD^c

^a*Departments of Pediatrics
Epidemiology, and Investigative Medicine
Yale University
New Haven, Conn*

^b*American Lyme Disease Foundation
Conn*

^c*Division of Infectious Diseases
New York Medical College
Valhalla*

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